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ABSTRACT

A palliative care support and training network was developed in a relatively isolated country area of the Barossa Valley in South Australia. The project was intended to help palliative care workers, volunteers, home carers, and others work collaboratively as a team (holistic model) for the purposes of mutually supporting, sharing information and learning experiences, and empowering each other to improve the quality of palliative care services in all settings. Stages of development included the following: selection of group leaders centered on the local hospitals; briefing of group leaders regarding their role, development of local support network, and sustaining of motivation and commitment from the group members; group leader meetings, the first face to face and the others at teleconferences; information exchange and learning program based on local needs and requests using interactive video conference facilities of Technical and Further Education institutions; development of learning resources/learning library; and formative evaluation. An independent evaluation found that the most successful outcome of the action research was the way in which the hierarchical nature of the professional structures within hospitals and between hospitals and nursing homes was addressed at the video conferences. (Appendixes to the report include the outline proposal, short reports on project progress, and a list of participants. Contains 44 references.) (YLB)

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# Someone to talk to
# and
# someone to listen

## The development of a support and learning network for palliative care workers in the country area of the Barossa Valley in South Australia

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**Report presented to the funding body**
***Southern Hospice Foundation Inc***
**Adelaide, South Australia**
**April 1994**

Centre for Education and Work
University of South Australia

CE 066 313



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## ACKNOWLEDGEMENTS

The concept of a support and learning network means that there are many people involved in making an idea work and the principal contributors have been noted at the back of this report. My thanks to them and to the palliative care workers in the Barossa and Districts Palliative Care Service, along with several other health care workers, community service students and interested observers who participated in the video conferences and the project generally, in some way or other.

Special thanks are due to the members of the Board of Management of the Southern Hospice Foundation who had both the vision and the generosity to support the ideas behind the project knowing it was a trial and error venture. I thank them for their confidence. It was a most satisfying learning project shared with high quality people, and, I trust, a useful contribution towards the development of a continously improving palliative care service. Any errors and shortfalls are mine alone.

Barry Elsey

# Someone to talk to
# and
# someone to listen

## THE DEVELOPMENT OF A SUPPORT AND LEARNING NETWORK FOR PALLIATIVE CARE WORKERS IN THE COUNTRY AREA OF THE BAROSSA VALLEY IN SOUTH AUSTRALIA

## THE ORIGINS OF THE PROJECT

A suitable starting point for this report is the brief telling of the story of how the project came into being. Towards the end of 1991 a conference (*Working Together*) was held in the Barossa valley dealing with various aspects of the provision of palliative care services in country areas of Australia. At one of the group discussions the problems of doing palliative care work in the relatively isolated circumstances of country areas, especially in the more rural and remote settings of this vast country, was elaborated several times over by participants. Somebody highlighted the point that the main problem was the absence of *"someone to talk to and someone to listen"*, which was such a crystal clear remark that it triggered off the leading thoughts behind this project and the title for the report. During the year that it took to secure funding there was ample opportunity to think about and explain how the central problem, so well expressed by the quoted remark, was to be addressed. *(Further details of the original thinking about the need for an action learning project and its intended scope and directions which formed the basis of the funding proposal to the Hospice Foundation are explained in appendix one)*

In addition to my own enthusiasm to turn a good idea, albeit in embryonic form, into a concrete project, I had the benefit of being able to outline them to the palliative care co-ordinator for the Barossa valley, Felicity Hage, an experienced nurse with an interest in making things happen through the formation of support groups and an open learning program focused on palliative care matters. The original idea was to employ Felicity Hage as the part time project worker, if funding was forthcoming, for clearly her current work in palliative care, grasp of the leading ideas, inter-personal skills, considerable local knowledge and connections made it possible to envisage making a positive start. When funding was made available she was unable to take up the job offer but found a suitable person, Diana Spencer, another local inhabitant in the Barossa and part time lecturer in Community Services in TAFE, also with a nursing background.

## THE IDEAL OUTCOMES AND OVERALL VISION OF THE PROJECT

Advocates of community and organisational development generally agree that it is important to have made a proper assessment of the need for change, together with a vision of outcomes of a planned change process, as tangible achievements over a given period of time. In the case of this one year long project, the need for change and development was assumed from the views expressed at the conference and readily agreed by the various people I subsequently consulted with in the process of getting the funding.

It would be a lie to claim that the vision for the ideal outcomes of the project came in one glorious flash of inspiration. Rather the ideas were implicit in the rough outlines of the main tasks and purposes and evolved steadily from the initial stages of the project as it unfolded and took shape in process. For the sake of a neat summary, though, the vision of the project, expressed as ideal outcomes are briefly described below in point form-

- Palliative care workers (PCWs), (comprising nurses, doctors, social workers, ancillaries, volunteers and anyone else considering themselves part of the wider team of workers) ***communicating with each other*** regularly about their work role responsibilities and concerns and talking through the everyday issues of working in palliative care.

- In the process of communicating with each other PCWs provide ***mutual support***, in the form of simple recognition of belonging to a group support network through to assistance with the practical aspects of care work and the much needed emotional support in dealing with the personally painful and challenging aspects of their work with patients, families and concerned others.

- In the process of providing group communication and mutual support, ***information is exchanged*** between members of the network about any aspects of palliative care work that is perceived by PCWs as relevant and useful to them.

- Arising from these processes, ***new learning*** by PCWs takes place about various aspects of palliative care work closely related to their perceptions of what they need to know, but also possibly including some incidental and "nice to know" learning.

- As a result of these activities PCWs regard themselves as both more ***confident*** about and ***competent*** with doing palliative care work, irrespective of their relative isolated working circumstances in a country area setting.

- Ideally all these processes of communication, information exchange, learning, personal support and empowerment ***continue after the funding runs out***, so that the support network project becomes self-sustaining.

- Ideally the lessons learned about the setting up and development of a group support network has ***wider applicability for other PCWs throughout the other rural and remote parts of country South Australia.*** Similarly, the support network and continuing education aspects of the project are seen as generally relevant to other kinds of social and health care workers in country areas, with developmental potential for

open learning using the new distance education technology and, possibly, some cost savings for staff training and development by enabling workers access to such facilities located nearer to their work locations.

It should be noted that each of these components of the overall vision comprised the criteria for the evaluation process for the project, both at a formative and summative stage. More of that subject later.

## SOME BACKGROUND SOURCES OF IDEAS AND INFORMATION

It should be noted that as an outsider, with no practical knowledge and experience of hospice and palliative care, I had to look for reinforcement to my leading ideas by scanning the easily available literature and talking to practitioners. For a working definition of hospice/palliative care I consulted the South Australian Health Commission, *Hospice Care Policy*, 1992; and for ideas about how a service worked from the 1992/93 financial year report of the *Palliative Care Unit and Southern Community Hospice Programme*; the history written by Dr Roger Hunt, *Community Hospice Programme: The First Six Years* published in 1989; and the current *Information Booklet* for staff and volunteers.

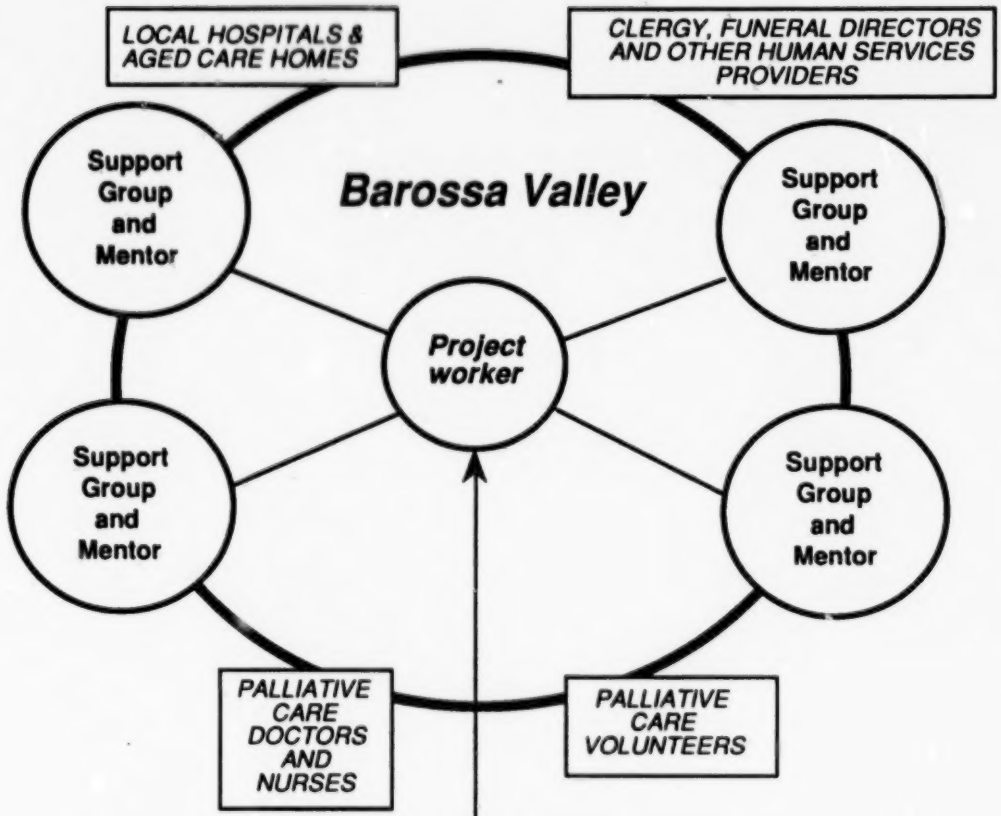
Also of relevance to the basic vision of the project, it was noted in scanning some of the current journals, that the practice of palliative care was sometimes linked to industrial work concepts such as best practice and bench marking, for the purpose of raising the performance and quality of service provision. Related to these ideas are similar ones such as confident and competent work and the implicit emphasis upon learning and continuous education and training for the improvement of work performance, through a sound grasp of current philosophies and practices in hospice and palliative care. A good example of this thinking is contained in the book, *Palliative Care of the Terminally Ill* by J F Hanratty, (1989) which explores the philosophy of terminal illness, pain management and the process of dying within a context of achieving a best practice, quality care service. As the contents of the subsequent video conference forums will show, the choice of talking and discussion topics by members of the support network closely reflected the interests and themes of such books and journal papers.

## THE BASIC CONCEPT AND DESIGN OF THE SUPPORT AND LEARNING NETWORK

As this is a report written specifically for the project sponsors, the Southern Area Hospice Foundation, it is not necessary to go into background descriptions of the palliative care service in Adelaide and its surroundings, or to define the meanings and purposes of palliative care and the community outreach, home based and hospice based aspects of the service, for these are already understood. In subsequent papers for journal publication such background context material is obviously useful, but not for this report.

What is important is to take up the story of the unfolding of the project through its successive stages of development, having first explained more about the original conception, which lies behind the vision statement made earlier in the text. This is best done by presenting the diagrammatic schema (over page) and briefly highlighting the key features.

## DEVELOPING A PALLIATIVE CARE SUPPORT AND TRAINING NETWORK IN A COUNTRY AREA OF SOUTH AUSTRALIA


LOCAL HOSPITALS & AGED CARE HOMES
CLERGY, FUNERAL DIRECTORS AND OTHER HUMAN SERVICES PROVIDERS
Barossa Valley
Support Group and Mentor
Support Group and Mentor
Project worker
Support Group and Mentor
Support Group and Mentor
PALLIATIVE CARE DOCTORS AND NURSES
PALLIATIVE CARE VOLUNTEERS

- *Mentor network formed and sustained by the project worker*
- *The learning needs of the support groups communicated to the link person in Adelaide*

**Project Director**

Collaboration with Department of Employment Technical and Further Education (DETAFE) using their interactive video conference facilities located at colleges in the Barossa, Gawler and Adelaide.

**PALLIATIVE CARE EXPERTISE LOCATED IN THE METROPOLITAN AREA**

drawing upon the knowledge and skills of palliative care doctors, nurses, social workers and counsellors, volunteer workers, political and business leaders, able to focus upon all aspects of the subject from complementary perspectives.

The ***three key elements*** of the project I want to highlight are focused on-

- the formation and maintenance of the support groups;
- the open and distance learning aspects of the group activities;
- and the roles of the project worker and director respectively in keeping the overall direction reasonably on track but also flexible to allow for local developments specific to each group.

These three issues will be written about shortly. The explanatory style used in this particular part of the report is drawn from the journal and commentary of the Barossa valley located worker, which she used to keep a record of the unfolding of the project, and the results of the formative evaluation, conducted by a university colleague and two students in 1993, that is, about three quarters way through. Both sources of information are used to reflect upon the project in terms of the relationship between the leading ideas and vision on the one hand and the actual outcomes, set within the project timelines, on the other hand. The spirit of the remarks made by myself as the principal author of the report are expressed in terms of the overall lessons learned and the implications for similar projects elsewhere, at another time and place, rather than reporting any notions of deficit and failure. The guiding spirit of the project was always to learn about the three main focus points through an open plan style of action and reflection.

Before detailing the key findings and analysis under the three aspects identified above it is useful to give a simple descriptive account of the stages of development of the project based on the actions and observations of the Barossa valley worker. The working notes kept by the project based worker are inserted, in edited form, to provide illustration of each successive stage of development.

## STAGES OF DEVELOPMENT OF THE SUPPORT NETWORK

**STAGE ONE: Selection of group leaders (mentors) centred on the local hospitals in the Barossa and involving the collaboration of Directors of Nursing as the key "gatekeepers"**

***Edited notes from the project worker***

Discussed with the Barossa palliative care co-ordinator (Felicity Hage) the best approach for developing the support network. We decided that using the local hospitals as centres for the networks would allow the group leaders (originally called group leaders) to access the greatest number of PCWs. We also included a group of general practitioners interested and involved in palliative care and an ecumenical group through the Barnabas Centre so that home carers could be accessed through their churches.

Made contact with Directors of Nursing at the Barossa hospitals; the local nursing home and the Lutheran Rest Home; the co-ordinator of Domiciliary Care; a local general practitioner; and the co-ordinator of the Barnabas Centre. Explained the nature and purpose of the project. The attributes of the group leaders were identified at the outset as being about the ability to relate effectively to network members, motivate and sustain their interest and involvement, and the capacity to attentively listen so as to focus on learning needs. An outgoing personality was also considered an asset. It was also clear early in the project that, at the very least, passive support was required from Directors of Nursing, in the case of local hospital group networks, if group leaders were to feel confident about their role and purpose. It was implicit in the foundation of the support networks that group leaders should feel free to decide their own best way of making things work and that the project worker would play a non-directive, support role.

Wrote short articles for the local newspapers outlining the project inviting interested people to join a support group.

**Key points for discussion later in the report**

In explaining and "selling" the project some mixed reactions were noted, mainly about the possibility that there might be "competition" with the existing palliative care service (which was easily explained); misgivings about using telephone conferences, preferring face-to-face communication (an example of not properly understanding the experimental nature of the project); suspicions that the project was too concerned with public sector workers (rather than the voluntary and non-government sector); and the expected problem of getting very busy people to act as group leaders.

On the positive side there was recognition of the need for more education about palliative care matters. The local GP held the opinion that the network would not be of special interest to doctors, nonetheless she agreed to act as a kind of link as well as group leader as part of her commitment to palliative care. There was some attention given to the thought that ministers of religion and funeral directors be invited to play a leadership role but it was decided to maintain a focus on the local hospitals and nursing homes as the key central points of the support networks, although the

ecumenical activities of the Barnabas Centre in the Barossa was considered a relevant choice for forming one of the group networks.

**STAGE TWO:** **Selection and orientation of group leaders (mentors) by explaining the purposes of the project, their role and working agenda and time frame, including their own time commitment.**
**Discuss with group leaders possible ways and means of developing local support networks and sustaining motivation and commitment from the group members**

***Actions taken by the project worker***
Appointment (unpaid) of group leaders at—

- Tanunda Hospital (actually the palliative care worker based at the hospital)
- Angaston Hospital and domiciliary care (a registered nurse-RN)
- The co-ordinator of the Barnabas Centre (representing local churches)
- Eudunda Hospital (the outreach nurse)
- Kapunda Hospital and Day Care Centre (a Clinical Nurse Consultant-CNC)
- Barossa Valley Nursing Home (an RN)
- Tanunda Lutheran Home (represented by a nursing assistant)
- A General Practitioner (representing other GPs with an interest in palliative care)

***Subsequent actions***
Each group leader received a detailed briefing of the nature and purpose of the project which emphasised its learn-by-doing spirit and form and the use of learning technology for distance communication.

Regular contact with the group leaders by telephone to check on progress and offer support. It was obvious that the group leaders had developed their own ideas about the nature and workings of their networks.

**Key points for discussion later in the report**

A few problems were starting to emerge over the way information and ideas were being communicated within some of the organisations involved in the project. One was strictly top down, another depended upon the group leader taking a positive attitude to particular matters, and a third was undermined by morale problems in the organisation as a whole. Additional to these was the personality and leadership attributes of the group leaders (mentors), some being more natural to the role than others.

**STAGE THREE:** **Commence group leader meetings, the first as a face to face gathering and the use of teleconferences for subsequent meetings to discuss local issues and emerging learning needs**

***Actions taken by the project worker and project director***
First group leaders meeting in which the project director joined in discussion about the basic ideas of the support and learning network. It was decided to

hold an initial video conference in early 1993 to become familiar with the technology. There was a marked reluctance, however, to use the telephone for conference purposes and the first attempt was unsuccessful.

***The project worker added:***
"Perhaps a greater push from me might have led to more teleconferences taking place but I saw my role as meeting their expressed needs to help them develop the network. I think the small area covered by the network means that most of the mentors (group leaders) knew each other and had some contact anyway".

**Key point for discussion later in the report**

The refusal to use the telephone for maintaining contact went against one of the key objectives of the project.

***The project worker wrote:***
"Held the first meeting on a face-to-face basis and then hoped to teleconference regularly. As the group leaders were nervous about videoconferencing it was decided that the first meeting would be using the facilities to familiarise them with the equipment. In hindsight I should have used the teleconference first so that they got into the habit of using it for communication but once they tried videoconferencing they were reluctant to try something else. It took me sometime to organise the first teleconference. I should have been more insistent, scheduling it first and then telling the group leaders to participate".

**STAGE FOUR: Commence information exchange and learning program based on local needs and requests and using the interactive video conference facilities of TAFE (now called Institutes of Vocational Education)**

Altogether seven video conferences were held and all except the first one was recorded on a VHS tape for subsequent viewing by members of the network groups. A topic outline of matters raised on a question and answer basis is listed below. Arising from the experience of the first video conference it was decided to run the others on a case history basis drawing upon real problems and issues of the practice of palliative care, which mostly explains the choice of topic for the question and answer forums.

Two sessions with volunteers and ancillary workers were designed to focus on more general aspects of philosophy and practice, taking account of some need to know matters such as the process of dying and the small but significant things that can be done to ensure there is a high level of quality communication with patients and families from those workers often playing a background support role.

The final video conference widened the frame of reference to include discussion on the moral and ethical concerns arising from doing palliative care.

***Additional notes from the project worker***
"The group leaders were very nervous about using the videoconference technology, especially the microphones, and their general coyness

remained for most of the other sessions. It meant the palliative care nurse and myself had to do most of the talking. Also, in spite of repeated requests to bring issues/questions to the videoconferences only three group leaders ever submitted case histories for discussion with the expert panels in Adelaide."

"Members tended to use the time after the videoconferences for discussing the issues raised. Group leaders seemed to find this useful as a time for boosting morale and airing views about everyday issues".

"One of the needs identified strongly by groups was the inclusion of non-professional workers, such as cleaners and canteen staff, in the exchange and sharing of information. To meet this need a special videoconference entitled "Back to Basics" was organised". At the videoconference ancillary staff were very shy to participate in the "live session" but afterwards they all had an amazing number of things to say about such matters as the attitude of nursing staff, the lack of information about patients and the need for de-briefing arrangements".

"One of the frustrating aspects of the videoconferences was the failure of group leaders and others to attend, even though they had promised, and not giving prior notice".

"It is possible that the interactive nature of the videoconferences did not suit the group leaders and network members because they are familiar with the lecturing method of learning. Putting the onus on them to come up with issues and questions was not only time consuming but was at odds with their mental set about education. They had no trouble coming up with broad topics, such as pain management, but then expected to be told what to think. They were also possibly reluctant to appear ignorant in front of their peers and the panel of experts by asking simple questions and to admit they did not understand a certain answer to a question".

**Topics covered at the interactive audio-visual conferences between the group leaders, other palliative care workers and the project worker in the Barossa Valley with various specialists and other contributors located in Adelaide**

**Medical and nursing information needs, such as-**

- management of nausea and vomiting
- management of pain
- treatment of constipation
- dealing with patient aggressiveness

The exchange of information and ideas moved from a focus on drugs and the management of physical needs to a wider concern with the emotional and spiritual aspects of dying. A key point to emerge was that there was ***no right way*** and that learning through experience was to best guide to practice, given the individual and various ways people actually go through the process of dying.

**Symptom and Pain Management**

- assessing pain and reactions to pain

- symptom control through drug treatments including the use of complimentary/alternative treatments and placebos
- the special problem of bone pain and phantom pain
- pain relief through clinical practices
- management of nausea and vomiting
- treatment of constipation
- the value of chemotherapy and radiotherapy
- psychological aspects of pain management, such as the loss of dignity and control
- the risks of over dosing on pain management drugs

**The Process of Dying**

- knowing about the way bodily functions change and cease to work
- knowing about the psychological process of letting go

**Understanding the process of dying**

This discussion focused on the needs of other than medical and nursing workers, that is, cleaning and catering staff, volunteers, as well as family and friends, to understand and know what to expect and how best to respond when people are in the final stages of life. It was agreed they had a valuable caring role and part of the support they should receive needs to be about understanding the process of dying. It was acknowledged that there was no one or right way about dying so information can only be of a general kind.

**Personal Coping**

- learning to cope with personal feelings of loss of a patient in one's care
- knowing yourself under testing personal circumstances and conditions
- earning to be and express oneself openly and honestly

**Interpersonal Communication**

- knowing what to say to a patient and family members when dying and death comes up in conversation
- knowing what to do when words fail
- helping patients do their life review and accept reality
- dealing with difficult and aggressive patients
- dealing with the emotions of others
- knowing when and how to say "no" to unreasonable demands without harming relationships
- using simple language and demystifying medical jargon
- dealing with the problem of conflicting medical opinions and seeking consistency to provide security for home carers
- the value of working as a team
- dealing with guilt feelings experienced by family members
- the importance of knowing about when to keep a confidence

**Doing more about the learning and support needs of ancillary and volunteer workers involved in palliative care**

- findings ways and means of involving them more in the care plan and process through an education program and direct "hands on" participation

**Grief from loss and bereavement support**

- how to help the family immediately after a client's death
- feeling okay about expressing one's own loss and grief and knowing how to handle them

**STAGE FIVE: Develop learning resources/information library, such as video tapes of the conferences, booklets and pamphlets**

***The project worker reports***

"A video was made of every conference except the first because of the reluctance of the group leaders to be recorded (and some technical problems). Copies were made and distributed to each group leader so that network members who had been unable to attend could view the proceedings. Books and pamphlets were added to each hospital library and the books on palliative care matters, written by Professor Ian Maddocks and collaborators, were purchased by the palliative care co-ordinator".

**STAGE SIX: Continue the process of identifying concerns, fostering group support and providing for learning needs**

***The project worker made a number of observations about the behaviour of the group leaders***

"Some seem more successful than others although all claim they have passed on ideas and information from the videoconferences to network group members and in identifying further learning needs".

"It is disappointing that networking between group leaders did not develop further. Some of the reasons seem to be busy work schedules; being unprepared to make much effort to do any learning; having little in common with other network members; and not really having enough practical work experience of palliative care to ask questions and exchange ideas and information".

***Three months into the project the worker reported***

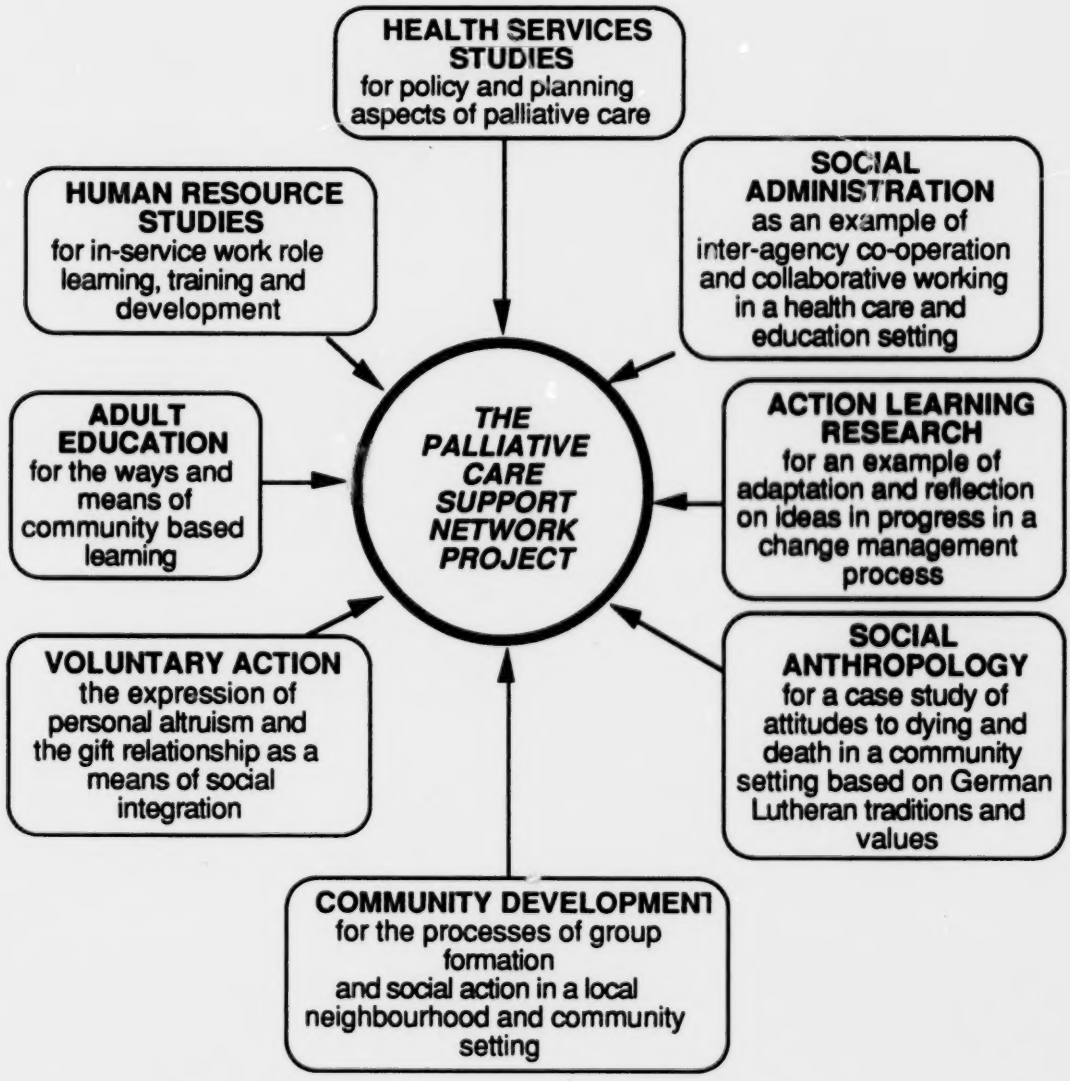
- Tanunda Hospital (where the palliative care worker is based): strong contacts in all the departments as well as membership of the hospital management committee.
- Kapunda Hospital: 7 to 8 contacts in different areas of the hospital.
- Eudunda Hospital: enormous network of contacts but the group leader seems happy with it this way. Looks like a strong network.
- Lutheran Rest Home: 7 to 8 contacts and looking like a well run scheme.
- General Practitioners: information from videoconferences handed over at their regular monthly meetings but doubts about the viability of the network and the enthusiasm and commitment of the group leader.
- Ecumenical group: one way communication only
- Angaston Hospital: disappointing with only a loose and informal network owing to staffing and morale problems
- Dropped the practice of issuing a newsletter as group leaders said they preferred word of mouth contact.
- Ongoing support usually by telephone. Group leaders usually felt their networks were working well given the demands on their work time. Irritated by their poor response in often failing to return phone calls or answering letters. Sometimes they seemed annoyed with me for chasing them up to respond to my offers of support and need for information exchange.

**STAGE SEVEN: Conduct formative evaluation focused on group formation, membership and network interaction (the sustainability question), the training and development aspects of the program (the learning question) and the roles of the project worker and director**

## KNOWLEDGE PERSPECTIVES OF THE PROJECT

The nature of the project can best be described as pragmatic in its thinking, that is, it was not built upon or driven by any consciously chosen theory or model, but instead was focused on addressing the practical problem expressed by the title of the report. Nevertheless it soon became apparent that the project did have links with bodies of knowledge that were both speculative or theoretical in nature and practical in application. These are outlined in the model below and explained briefly afterwards-

# KNOWLEDGE PERSPECTIVES OF THE PROJECT


HEALTH SERVICES STUDIES
for policy and planning aspects of palliative care
HUMAN RESOURCE STUDIES
for in-service work role learning, training and development
SOCIAL ADMINISTRATION
as an example of inter-agency co-operation and collaborative working in a health care and education setting
ADULT EDUCATION
for the ways and means of community based learning
THE PALLIATIVE CARE SUPPORT NETWORK PROJECT
ACTION LEARNING RESEARCH
for an example of adaptation and reflection on ideas in progress in a change management process
VOLUNTARY ACTION
the expression of personal altruism and the gift relationship as a means of social integration
SOCIAL ANTHROPOLOGY
for a case study of attitudes to dying and death in a community setting based on German Lutheran traditions and values
COMMUNITY DEVELOPMENT
for the processes of group formation and social action in a local neighbourhood and community setting

**Health Services and Social Administration**
The project highlights the multidiscipline nature of palliative care provision which has to be taken into account when involved in the strategic planning and policy formation process. Achieving good quality inter-agency co-operation both within the health care system and with the education and training field is clearly a relevant performance benchmark for best practice in the provision of palliative care services. It is possible to further explore the theory base by relating palliative care provision to different models of social welfare policy and their respective ideological foundations. Palliative care provision seems to be based on a minimal welfare model, which is not about meanness but rather about a reasonably publicly funded "safety net" to enable people to die in modest dignity and comfort, for which extra psychological and material value might be added through voluntary contribution and personal savings.

**Action Learning Research**
The process of research is focused on solving a problem by getting practically involved and using the experience as the basis of learning and personal reflection, usually shared with others. Action research has to be open and flexible, willing to change course and re-think approaches in the light of problems and experiences as they arise. In that sense it is a useful method in the very action oriented world of providing palliative care to patients and the learning and mutual support for workers.

**Social Anthropology**
The project touched on attitudes to death and dying which seemed to relate to traditional cultural and religious values and practices particular to the history of social group and community settlement in the Barossa valley. This way of thinking about palliative care is useful in the context of a multi-cultural society generally and geographical communities particularly. An awareness of these anthropological aspects of palliative care can only raise the level of understanding of the individual and family context of death and dying.

**Community Development**
As indicated above, the Barossa valley appears to be a tight knit and somewhat closed community which proved to be both an asset and a little nuisance in forming the support groups. The approach of the project was loosely based on a network model of community development, attempting to form clusters of self supporting groups focused by a group leader and linked together by the project team workers for the purposes of assisting their support and learning activities.

**Voluntary Action**
Palliative care depends greatly on the commitment and inter-personal and practical skills of volunteer workers and their involvement, support and learning is an integral part of a quality focused team based approach to provision. The meaning of voluntary action implied in the project design was very concerned with the ideal of empowering volunteers to give their best and benefit themselves at the same time.

**Adult Education**
The approach of the project emphasised the importance of informal learning through group interaction and reasonably structured formal learning through the interactive video conferences and follow up discussions. The

model of adult education was located within the work training one but infused with the style of the liberal humanist one as well.

**Human Resource Management and Development**
Relating to the above, it was clear that the in-service skills training being developed was concerned with the overall enhancement of work performance, within a team based and organisational goals setting, focused on the ideas of continuous improvement in the quality of service care and provision.

## INDEPENDENT EVALUATION OF THE PROJECT

What follows are the observations and conclusions of the independent evaluator who volunteered her services and that of two students from the community development course at the University of South Australia. It should be noted that the fortunate recruitment of Dr Janet McIntyre, a social anthropologist of several years standing with experience in rural and urban fieldwork and considerable academic achievement, was a stroke of luck arising from her hearing me speak about the project at a conference and subsequent willingness to act the role of independent evaluator. I provided the overall framework for the evaluation, which is based on the original vision and ideal outcomes and a more specific set of thematic concerns. The evaluation, set within the main body of the report, addresses the main concerns of the project director, being matters related to the overall effectiveness of the project and what has been learned from the experience of setting up and running the learning and support network that would be useful to know for other comparable ventures.

**Report of the independent evaluator—**

### AN EVALUATION OF THE PALLIATIVE CARE SUPPORT NETWORK IN THE BAROSSA VALLEY

### SUMMARY

- The educational content of the video conferences on palliative care was holistic in its approach and the networks attempted to include all those who played a role in increasing the comfort levels of the dying.

- It was clear to some of the project participants that if it was assumed that palliative care was about considering the whole person, then it involved the participation and cooperation of members of the patient's family, hospital or nursing home cleaners, hairdressers, occupational therapists, cooks, social workers, nurses and doctors.

- Ancillary workers have always been involved in palliative care, but in the past the full importance of their role in holistic care had not been explicitly recognised. During the video conference discussion and the process of networking across the disciplines, the hierarchical nature of palliative care in hospitals, nursing homes was questioned. Whereas previously the ancillary workers who, for instance cleaned and cooked were considered to be outside "the biomedical team", as a result of the process of participating in the video conferences and networking, their role as an integral part of the process of holistic palliative care has gained increased attention. The needs of ancillary workers for debriefing or counselling are however areas which still need to be addressed in practice.

- The project aimed to network across the limits of the barriers of organisational and professional stratification by means of face-to-face and distance communication, in order to learn and pass on information which could facilitate holistic care.

- The networks for palliative carers in the Barossa comprised members who were both medical professionals and ancillary staff. They were set up by group leaders who liaised with a project worker who provided the central focus and administered the project.

- The successful networking styles built on existing personal contacts, the unsuccessful networks were formal and impersonal and made little attempt to bridge the communication gaps across ancillary workers, professionals and concerned people in the community.

- Within each organisational context the staff also appeared to operate in isolation from one another, because of professional divisions within the nursing staff hierarchy, between registered and unregistered nurses and between the nursing staff and medical doctors and between the ancillary workers and professional staff.

- An analysis of the data revealed that the hospitals and nursing homes prior to the project also tended to operate in isolation from one another. This was perceived to be because the hospital staff considered themselves to be superior to the nursing home staff.

- As a result of the key intervention components of the project, namely: video conferences and networking—at best, professional and non-professional staff in hospitals and nursing homes were encouraged to talk to one another as a result of group participation at the video conferences—at worst, the staff (professional and non professional) began to think about the contribution made by other members of the team. This comprised a shift in focus in both hospital and nursing home management of care away from narrow biomedical models of care to holistic models which acknowledge the role played by auxiliaries.

- By holistic we mean that instead of treating the physical symptoms in narrow physical and medical terms, the whole human being (spiritual, mental and physical) is addressed. Quality of life and quality of death are considered very important, not merely ameliorating symptoms.

To sum, up the most successful outcome of the action research was the way in which the hierarchical nature of the professional structures within hospitals and between hospitals and nursing homes was addressed at the video conferences. The networks served, if **not to translate some of the ideas and issues** raised at the conference discussions into practice, at least **to introduce the relevance of these aspects of organisational management and the philosophy of care to hospital and nursing home environments.**

The distance education method has paradoxically made it possible for alienated groups in hospitals to speak with one another and for staff in marginalised nursing homes to speak with hospital staff, this contributed towards breaking down some of the barriers.

## INTRODUCTION

The design of the project is elegant in its simplicity. The organisational context of the palliative care networks set up by the qualified palliative care nursing co-ordinator (PC) and the Project Worker (PW) was hospital, nursing home and community based. The eight group leaders were based at five hospitals and two nursing homes and at an interdenominational church organisation. The group leaders were briefed by the PC and PW about their role as facilitators of learning.

**Adult learning comprised:**

- Video conferences were set up to which the group leaders and members of the respective networks were invited together with experts who gave specialist input and lead discussion.
- A telephone conference to keep the group leaders in contact with the palliative care clinical nurse (PC) who is well-known in the Barossa and the project worker (PW).
- Introduction of these ideas into the work context through networking.

**The evaluation addressed the following:**

- project design and location
- rationale for the project
- extent to which the pilot project existed in isolation
- desired outcomes of the project
- assumptions underpinning the formative evaluation and the rationale for the evaluation
- discussion of intended and unintended outcomes and the implementation processes-

    1. types of networking style within hospitals and nursing homes influenced by the type of organisational communication and the management structures within which the group leaders operated
    2. group membership and function
    3. the role and process of leading groups
    4. the role of the Project Worker and Project Director
    5. the role played by the palliative care nurse in supporting group leaders, in keeping members motivated, focused and able to identify and express their needs
    6. the extent to which the group leaders relied on the project worker to initiate ideas and activities
    7. The perceived role of mentors or group leaders.

- The extent to which the educational content met the members' needs
- Different stakeholders' perceptions of the project
- Opposition to the project and non participation
- The most successful outcome of the project as far as the group leaders and the evaluator were concerned (see McIntyre 1994).

## THE PROJECT DESIGN AND LOCATION

**Pros and cons of choosing the Barossa for the action research project**

The Barossa is a community with a history of settlement by the Cornish and Lutheran Germans. It has a history of viticulture and hardworking, religious citizens.

In some respects it provided a useful context for exploring the relevance of a network for supporting palliative carers, because it is a small face-to-face community where many of the local families have known one another for generations.

An examination of the South Australian Health Atlas (1990) reveals that the socio-economic status of the local people of the Barossa Valley is not uniform. In the Barossa there are 4,635 people who are 65 years and older. The majority have an income between $12000 and $40000. The ageing population are middle income earners on the whole. An examination of the Social Health Atlas, however also indicates that the number of car owners is lower than would be expected for this area and the homogeneity of living standards obscures some of the lower living standards experienced by single parents, people who are unemployed and have low educational qualifications.

For the elderly who do not drive, low income earners and the unemployed, the isolation of the Barossa and the reliance of local services is greater than for the professional, middle classes which make up the recognised core of the professional palliative carers.

The outer metropolitan areas of Adelaide are underserviced as far as health care is concerned and the providers of health care need a support network in order to be able to *be there for one another*, in order to avoid burnout and in order to help them remain up to date with the latest methods and ideas about palliative care.

The **drawback** of choosing the Barossa for testing out the extent to which a palliative care support network is able to maintain itself and assist in adult education through the use of distance education methods initially appeared to be two-fold:

First, the usefulness of a palliative care support network based on distance learning methods in an area such as the Barossa, which is not as remote from metropolitan Adelaide as other less well served areas further North, appeared questionable, because it did not allow for a full appreciation of distance learning. But as mentioned above, metropolitan Adelaide is more readily accessible for some carers than others. Some of the professional informants commented that they did attend conferences in Adelaide and therefore did not feel that video-conferences were useful for them. This is not however necessarily true for all the carers in the community outside the organisational context or the ancillary workers.

Second, in a sense the fabric of the face to face *community* provided a ready-made network and the palliative care nurse (PC) had worked successfully to build a system of care and educational support.

The process of extending a palliative care support network on already existing or indigenous networks in a stable community initially **appeared** to be fairly straightforward. The problem with working in this tightly knit society, where a palliative care network already existed, was that the actual process of setting up a network from scratch could not be studied.

But closer investigation established that the palliative care network which Elsey, PW and the PC extended, differed from existing formal networks in that it was interdisciplinary and crossed professional, role and organisational boundaries. This proved to be a challenge for some of the fixed ideas about the professional, biomedical nature of palliative care held by some of the professional medical and nursing staff. It was also a challenge for the taken for granted ideas about the Barossa status quo, namely respect for those *better qualified* or *formally qualified* and a social distance based on formal role expectations.

The method of adult education using distance education which also cut across social distances was a first for the area.

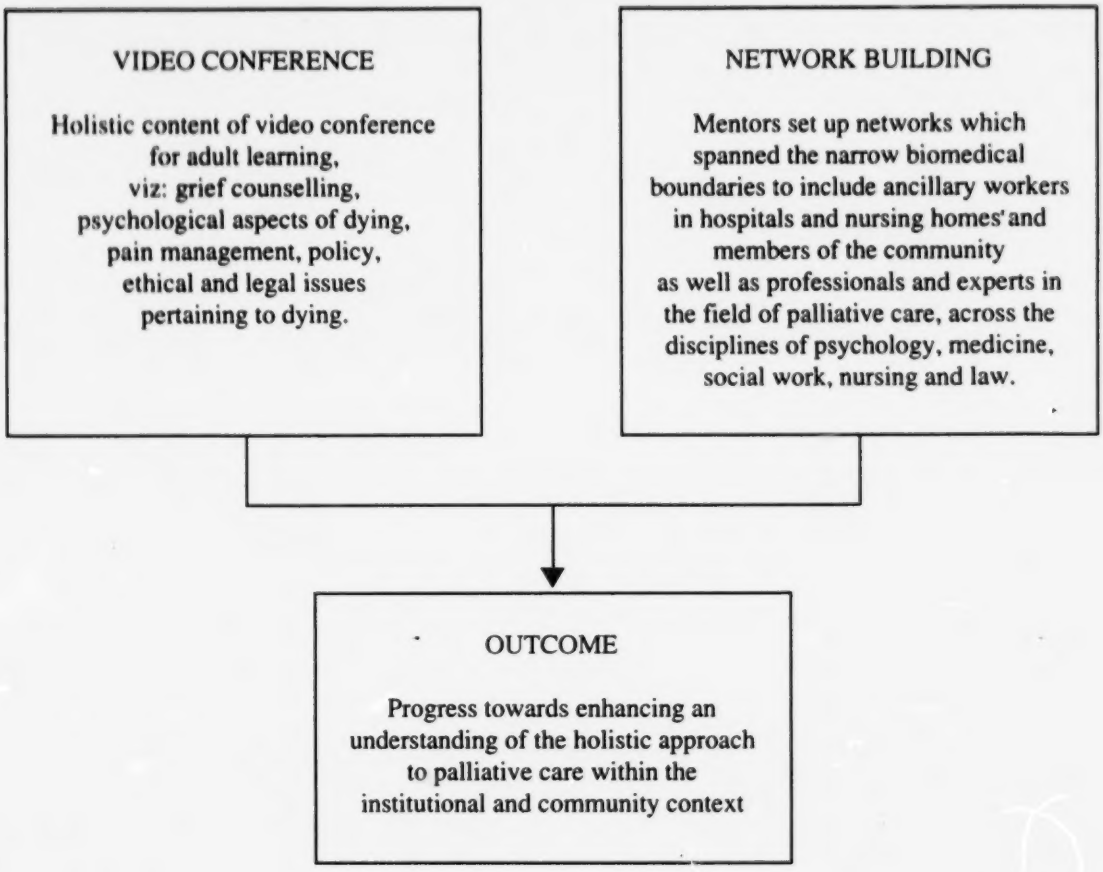
Another problem was the obvious reticence some of the informants felt about talking openly, given the hierarchical nature of hospitals and nursing homes and the close friendship ties which cut across work responsibilities. The distance between work life in the public sector and private life is small in a face-to-face community.

## THE RATIONALE FOR THE PROJECT

A case-work approach to delivering care and advice in isolation and on behalf of others is draining and demanding for one palliative care specialist, no matter how dedicated, respected and capable she is. A community development approach to palliative care aimed to draw in a wide range of professional and ancillary workers in hospitals, nursing homes and members from the community to assist in the delivery of a more comprehensive service. An attempt was made to offer an alternative to the biomedical model of palliative care, namely an holistic, team approach making use of professionals and ancillary workers within and outside the hospital or nursing home setting.

In the evaluation the points of view of all the stakeholders were considered, as were the intended and unintended outcomes of the project.

**DIAGRAM 1: THE KEY COMPONENTS OF THE PROJECT**


VIDEO CONFERENCE
Holistic content of video conference for adult learning, viz: grief counselling, psychological aspects of dying, pain management, policy, ethical and legal issues pertaining to dying.
NETWORK BUILDING
Mentors set up networks which spanned the narrow biomedical boundaries to include ancillary workers in hospitals and nursing homes and members of the community as well as professionals and experts in the field of palliative care, across the disciplines of psychology, medicine, social work, nursing and law.
OUTCOME
Progress towards enhancing an understanding of the holistic approach to palliative care within the institutional and community context

## THE DESIRED OUTCOMES OF THE PROJECT

The goal was to set up "self supporting voluntary groups of palliative care workers regularly talking to each other about their concerns and needs for personal support, training and development" (Elsey, 1993).

We were asked to evaluate the following particular outcomes:

- the extent to which group formation had occurred and the sustainability of the project once it had been set up.
- group membership
- the way in which the networks operated.
- the content of what had been learned through attending the video conferences
- the participants' perceptions of the distance learning methods.

The goal of the evaluation was to study not merely the intended outcomes but the whole process of implementation, including unintended outcomes, and in so doing to obtain an idea of the way in which the networking processes took place and the extent to which different types of networking

style influenced the communication and the extent to which learning took place.

Thus the perceived needs of the participants, the process of implementing the project and the intended and unintended outcomes were the focus of our attention.

## THE EVALUATION METHOD: THE RATIONALE FOR THE EVALUATION AND ASSUMPTIONS UNDERPINNING THE FORMATIVE EVALUATION

A formative evaluation was undertaken so that the process of project formation could be studied. It involved our participation and attendance of some of the video conferences, collection of data from semi-structured and unstructured interviews, a focus group discussion, tracing the existing networks of group leaders, telephone interviews and viewing the video material.

The method of implementation and evaluation was one of action research, namely: "to learn by doing". Action research is a process of learning, reflecting on the new insights gained and implementing them in a series of "feedback spirals" (Erskine, 1985, Lewin, 1946, Louw, 1984, Mills 1986, Rappoport,1970).

The process of gathering data is based on the assumption that we can get closer to *truth* through dialogue and "intersubjective sharing" (Mead 1984, Romm 1986, McIntyre 1994 in progress) with the stakeholders (Guba and Lincoln 1989) in the project.

Ethnography (1) which strives to make sense of the emic or insiders' understanding of reality makes use of methods such as case studies, participant observation and networking.

In a spiral of implementation and learning, an attempt was made to derive lessons from the successes and failures of the project and to make recommendations about the usefulness of:

- the method of action research
- the networking design for palliative care and other community development initiatives
- the usefulness of adult education based on distance education methods for remote areas in Australia

The model of evaluation which we used was shaped by our assumptions about theory and methodology, hence a brief discussion of these is appropriate at this point.

The theoretical approach followed was critical and humanistic. It is assumed that collaboration is the key to participatory action research. For this to occur a sense of partnership needed to be established, based on the assumptions that all life experience contributes to understanding the paradoxical nature of reality.

The community development initiative paid attention to:

- the individual creativity of the participant group leaders who were therefore encouraged to set up the networks in the way in which they preferred and
- the importance of forging cooperation across the different disciplines and sectors within the community.

It was assumed that as a researcher my role was to understand the perceptions of the various stakeholders in the project. It was also accepted that the perceptions of the participants could differ depending on the different values which they held about the role of the professional biomedical team and the way in which holistic care rather than merely symptom management could be achieved.

The spirit of this evaluation process can be summed up by quoting Guba and Lincoln (1989:8):

> "The findings are not facts in some ultimate sense but are, instead literally created through an interactive process that includes the evaluator (so much for objectivity) as well as the many stakeholders that are put at some risk by the evaluation..."

Essentially the goal of the evaluation was to ascertain which aspects of the project were successful and which could be improved upon in order to better understand the emic (or insider) perception of all the stakeholders' needs.

The way in which qualitative data was obtained was through talking with different stakeholders in the project. These included:

- the initiators, Barry Elsey, a senior university lecturer, and the PC, a clinical palliative care nurse
- the group leaders who are registered nurses
- the group leaders who are unregistered nurses
- a general practitioner
- the Project Worker (PW) appointed by Elsey and the PC to facilitate the setting up of the video conferences and telephone conferences
- the Nursing Directors
- the members of the networks comprising ancillary ie non professional staff within the hospital and nursing home setting and outside these institutions
- members of the network who are church based

The pilot project aimed to enable the participants to learn by doing. In the process of learning, the strengths and weaknesses of the project were discovered and noted in order to make recommendations for the implementation of other similar initiatives using video conferences as a means of:

- educating adults
- setting up and maintaining networks for learning and support purposes.

Because the evaluation goal was to understand the processes involved in setting up the network, not merely the extent to which the desired outcomes had been achieved , we chose to use qualitative research methods for assessment.

## DISCUSSION OF OUTCOMES

**Support Group Membership and Function**

The membership appeared to be determined by the group leaders who were encouraged to choose a wide spectrum of participants, both professional and non professional people to join their networks. Members comprised staff from the following categories: hairdresser, day carer, nurse, hostel staff member, night staff nurse, housekeeper, hostel supervisor and social worker, diversional therapist, cook, general domestic, registered nurse and enrolled nurse.

The composition of the networks reflected the following:

- the extent to which the leader believed in maintaining the hospital hierarchy
- the amount of time the leaders were prepared to spend on the project
- whether they understood the project objectives
- whether they thought that nurses and doctors should preserve the right to discuss palliative care
- the status of the group leader also influenced the ability to act as facilitator. (For instance a Registered nurse could not persuade fully qualified nurses to attend the video-conferences or even to view the video tapes, because of her lower status in the hospital hierarchy)
- whether or not the Nursing Director was in support of the project was a crucial determinant of the success of a network

Networks formed around the group leaders but tended to be isolated from one another even in the most effective group leader network. **Inter group leader** networking did not occur except at the video-conferences and during the teleconference. These group leaders were the lynch pins of the separate networks but they met only at the video conferences.

**Types of networking style within hospitals and nursing homes were influenced by the type of organisational communication and the management structures within which the group leaders operated**

The following typology illustrates the different types of networks which had different approaches to communication and learning and mentoring styles. The sort of networking style was not dictated by the project worker or by the palliative care nurse.

**THE FOLLOWING NETWORKING STYLES WERE EVIDENT: NETWORKS RANGED FROM SMALL, FACE-TO-FACE TYPES TO LARGE, IMPERSONAL MAIL-OUTS**

1. **Small face-to-face network:**
   - a small intimate network, within two of the nursing homes
   - face-to-face communication with all members
   - regular contacts
   - informal contact during the course of the working day

2. **Networking across sections within a hospital:**
   - face-to-face communication with facilitators in the different sections of the hospital
   - regular meetings with facilitators
   - formal meetings plus informal contact in the course of their daily routine
   - regular follow-ups based on meeting a key contact person in a hospital who in turn set up satellite networks within the organisation.

3. **Networking across organisations, facilitated by the palliative care nurse, who is widely known and respected:**
   - face to face communication
   - regular meetings
   - formal, programmed meetings

4. **Across sections within a hospital:**
   - communication by means of noticeboards or duty book
   - irregular meetings
   - formal communication

5. **Large, impersonal networks:**
   Regular mailouts to 31 church congregations provided the only form of communication from a group leader based at a Christian Community Centre.

In the smaller networks, regular face to face communication within the group was successfully achieved whereas in Type 5, the vast mail-out network, this was not achieved. There was no feedback from the people on the mailing list, according to the informant, despite an attempt to include the wider community. She understood that the impersonal nature of the mass mailouts was unsuccessful. In an era of information overload and junk mail, unless communication is personalised in community development initiatives, it has little chance of succeeding!

These network types form a continuum of networking styles. The most successful were 1, 2 and 3. The least successful were 4 and 5. The successful networking styles built on existing personal contacts, the unsuccessful networks were formal and impersonal and made little attempt to bridge the communication gaps across ancillary workers, professionals and concerned people in the community.

The group leaders were supposed to "keep the groups motivated, committed focused on the concerns of the members and to identify their needs.

**DIAGRAM 2: NETWORK TYPES**

| NETWORK TYPES | | DESCRIPTION OF COMMUNICATION STYLE | FACILITATION METHOD AND ORGANISATION CONTEXT | SPAN OF INFORMATION NETWORK |
|---|---|---|---|---|
| 1 | Successful | Small, intimate face-to-face communication | Three mentors who interact with interested participants in each organisation supported by the director of nursing | Small, within parts of the respective organisations |
| 2 | | Network across sections of an organisation based on delegation | One mentor who delegates responsibility to other facilitators in each section of the hospitals. She is highly motivated and receives support from the director of nursing | Across all sectors of the hospital |
| 3 | | Large personal network across organisations | PCN's network based on regular formal meetings | Across organisation |
| 4 | Unsuccessful | Impersonal network | One mentor with little authority or support who used notice boards and duty book | Across sections of an organisation |
| 5 | | Large mailouts across congregations | One mentor with little time to devote to personal contacts | Across church congregations |
| 6 | | Non-participation | One mentor - a GP who did not understand the project | |

## THE ROLES OF THE PROJECT WORKER, DIRECTOR AND THE ROLES OF THE MENTORS

### The role and process of leading groups

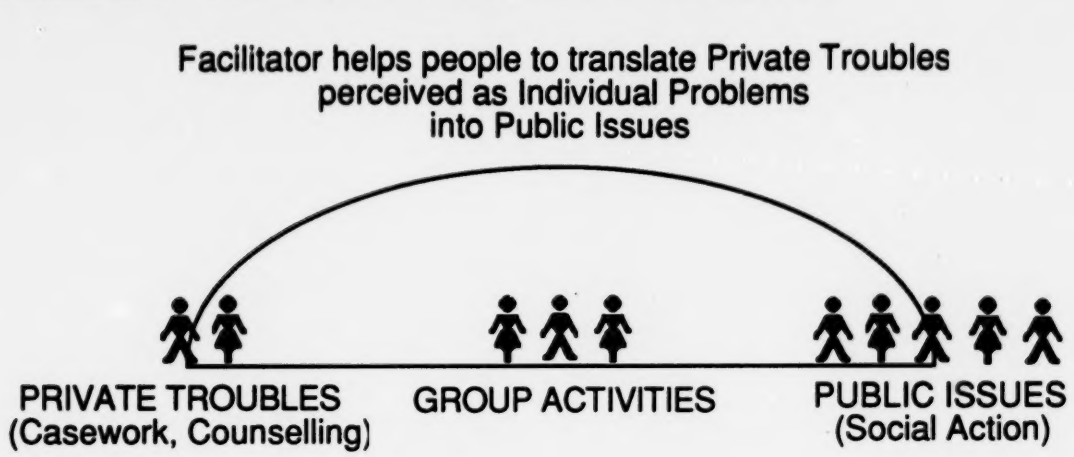
Barry Elsey, the project director, based in metropolitan Adelaide kept in telephone contact with the project worker (PW) who brought to the project considerable inside knowledge of the community where she had lived all her life. Besides providing the PW and the local Palliative Care Co-ordinator (PC) with a proposal and working with them on developing a strategy to meet the desired outcomes, he had to use his terminology a "focused, indirect approach" to facilitating the setting up of the project. Essentially he managed to enthuse the project worker and the palliative care co-ordinator who are both long standing Barossa residents, whose families have been involved in viticulture for generations, to mobilise and build on their existing networks. The strength of the initiative lay in shaping existing local networks for the purpose of community development and education purposes.

The project worker liaised with the eight mentors or group leaders, rather than with the members of the respective networks. She attempted to be led by the expressed needs of the group as they were articulated by the leaders. Unfortunately all the group leaders were professionals and in some cases not sufficiently perceptive of the needs of the ancillary staff.

### The role played by the palliative care nurse in supporting group leaders, in keeping members motivated, focused and able to identify and express their needs

The palliative care nurse (PC), one of eight in rural South Australia, was well thought of by all the stakeholders in the project. She was universally praised for her role, to the extent that two of the group leaders could not understand why there needed to be a palliative care network. The attitude was that:" [The PC] can and does do a wonderful job". This was in part due to their case-work approach to palliative care, rather than a holist understanding of the community development continuum.

**DIAGRAM 3: COMMUNITY DEVELOPMENT CONTINUUM**




Sources: Jackson et al. 1989, C Wright Mills 1975

The diagram illustrates the key assumption in community development that instead of working in isolation and dealing with *private troubles*, an attempt is made to work on these in groups of people who share similar problems and have a shared interest in finding solutions. C Wright Mills (1975) referred to the process of translating "private troubles" into "shared public issues", so that action could be taken to address them. In palliative care it is essential to work in a supportive network and not in isolation, in order to avoid burnout.

The importance of a strong leader is vital for encouraging group leaders to help set up the framework of a network. In the areas where the PC was active, the networks operated more strongly than in areas further away. She appointed the Project Worker to help her.

**The extent to which the group leaders relied on the project worker to initiate ideas and activities**

They were briefed by the Project Worker (PW) in person or by the PC or in some instances by the Director of Nursing who handed on a pamphlet about the project. This was followed up by a discussion. In instances where the networks did not work adequately it was because the full nature of the project was not understood. The briefing stage was vital to the success of the project.

The group leaders saw their role as intermediaries between PW and the group members. The setting up of the network was left to each leader and they opted for very different networking styles. Two group leaders from the nursing homes described their role as conduits for information. They saw their role as a *water shed* to pass on information to the other members and did not see themselves as being creative members of the project. The group leaders at Angaston and Eudunda saw their role as group leader as continuous with other nursing roles.

In five of the eight networks, the group leaders had a good understanding of the project. In two instances group leaders who operated within a narrowly

biomedical model, could not understand the holistic dimensions of a palliative support network, which could forge a bond across biomedical and non biomedical staff within the institutional setting and beyond. In one case, the group leader (based at he Ecumenical centre) was unable to carry out her responsibilities because she had too many other commitments.

**Perceived role of the mentors or group leaders**

In order to assess the extent to which group leaders had built up networks around them, they were asked to distribute a questionnaire to their group members or to organise a focus group discussion with members of their network. In this way we attempted to determine the extent of their networks, the way in which they functioned and the extent to which they had gained in confidence, skills or information as a result of their membership.

This section of the evaluation was not completed, due to the poor return of the question schedules partly because it assumed a high literacy level.

An attempt was made to establish the extent to which the group leaders perception of the project was supported by the group members by triangulating their perceptions against those of the leaders.

## LEARNING ASPECTS OF THE SUPPORT GROUP

**DIFFERENT STAKEHOLDERS PERCEPTIONS OF THE PROJECT:**

- The initiators Barry Elsey, a senior lecturer at the University of South Australia and PC, a clinical palliative care nurse and PC, the co-ordinator appointed by Barry and Felicity to facilitate the setting up of the video conferences and telephone conferences.

  They saw it as a means of trying out adult education methods such as video conferences to enhance the support for palliative carers in the Barossa. The forging of networks between university, TAFE, professionals in hospitals and nursing homes in the Barossa and Adelaide was central to the project.

- Sylvia Healy, TAFE lecturer who provided technical support at all the video conferences, lives in the Barossa near to the co-ordinator.

  Saw it as an opportunity to forge links between university and TAFE in a community based adult education project.

- The group leaders who were registered nurses saw it as part of their responsibility as nurses.

- The group leaders who were unregistered nurses saw it as a learning opportunity.

- A general practitioner saw it as superfluous to the education of professionals.

- The directors of nursing. Some were much more supportive than others depending on their understanding of the project.

  In hospital contexts where the directors did not understand the value of the project, there was little success, because the staff were not encouraged to participate.

- The members of the networks comprising ancillary ie non professional staff within the hospital and nursing home setting and outside these institutions. Participants thought that the project was a step in the right direction, in so far as it addressed the hierarchical nature of care and the need for more communication across team members.

## EXTENT TO WHICH THE GROUP MET MEMBERS' NEEDS

**Information exchange**

The holistic approach to palliative care was taught through interdisciplinary team teaching using video and teleconferences and the forging of palliative care networks across disciplines in the hospitals and nursing homes.

## PROS AND CONS OF VIDEO AND TELECONFERENCES ACCORDING TO THE GROUP LEADERS

**PROS of video conferences**

- saves time and enables one to be in contact with others whilst still in the ward
- it is inexpensive
- integrates people within and between organisations
- the technology became easier to master after the first one
- new perspectives on palliative care

It integrates us with other professionals in and outside the Barossa:

> "I find the telephone conference most practical, because it does not mean that we have to take time off work. We talked about how things were going in our own situation and gave feedback on the videos."

It saves time :

> "Whilst you are working in the dementia ward and doing your work you can talk with other groups in the Barossa"

The group leaders from the nursing homes stressed that teleconferences and video conferences broke to some extent the sense of isolation felt by nursing home workers who have been seen in their opinion to be *second string* professionally in comparison with hospitals in the Barossa:

> "Good staff are perceived to work at hospitals not nursing homes."

A registered nurse confided that she re-watched the tape of the video conference on pain management. She found it particularly helpful, because they advocated holistic care beyond drug treatment, which in her capacity she was not allowed to prescribe. She suggested an index to an edited version of the tapes which would facilitate their use as an easily accessible reference tool.

**CONS of video conference methods**

- anti video technology
- anti the concept of distance education
- lack of agendas
- lack of written information on the content before the video conferences

These methods were perceived by the sharpest critics to be unnecessary because metropolitan Adelaide is not a great distance from the Barossa. It is not so readily accessible for those with low incomes without motor vehicles who provide care within the home environment or who are ancillary workers with incomes lower than the professionals. The professional group leaders perceptions, however did not necessarily overlap with the experience of the auxiliary workers and volunteers in palliative care.

Face-to-face contact was stressed by a self confessed "member of the old school", a clinical nurse, as a form of learning preferable to video conferences. She conceded that video-conferences and the visit by the dietitian to the kitchen staff were very important in so far as they "improved staff morale and relations".

One informant said that the length (three hours) was far too long for the video conferences. This informant was the project's sharpest critic:

> "The video conferences are like watching paint dry. PW did not send out the case material to the participants of the first video conference in advance. One video conference was enough. If we had the case material in advance we could have prepared better. Its no good thinking about what you could have said afterwards."

**CONS of teleconferences**

- need a set agenda mailed out to people in advance

The telephone conference was hailed with mixed responses. Some said that it was a useful, time-saving way of keeping in touch with one another. Others thought that a set agenda would facilitate the suggested that teleconferences conferences could be better organised. Participants are busy and cannot waste time on pleasantries and unstructured conversation. One participant was very embarrassed because she could not gauge whether she was boring other people. She wanted to fill some of the embarrassing silences.

**Mutual support**

**Lack of time in busy schedules**

Many of the group leaders stressed that this work had to be done in their own time and was unpaid. This is problematic for people who are already working long hours.

**Administrative weaknesses and inefficiency**

Some justifiable criticism of administrative lapses such as the lack of agendas for the teleconferences and case notes from the video-conferences was expressed. The sharpest critic, a general practitioner expressed her frustration as follows:

> "Everything is a huge jumble, have not been to phone conferences. How can these work without a definite agenda?"

**Palliative care was seen in narrow biomedical terms**

Opposition to the project and non participation flowed from the assumption that the professional responsibility of palliative care should be dealt with by professionals and there was little need to train or empower others.

Critics could not understand that the palliative care network could benefit all the staff not merely the non professional staff. A feeling that they could

access the information from the local doctors and from the PC was expressed by those who were most negative. This perception can be summed up by quoting one of the informants who decided not to participate as a group leader:

> "[The PC] already does a great deal of the educative work and so in a sense the whole project is superfluous. "It is reproducing what is already being done...if allied health professionals do not ask it is their problem, you can only spoon-feed people so far [for help/advice)...it was great to have more contact with the nursing homes though. The project spread has been too broad. Maybe the catering and cleaning staff should just get together. From my point of view it is a chance to help ancillary workers....I already do this kind of educative work....everyone knows that I am the GP who has a particular interest in palliative care. The Barossa Medical Association already do this."

The same critic did, however concede the value the project played in acknowledging the role played by ancillary workers:

> "I do think the ancillary staff have benefited and I think the visit of the dietitian was good [for the kitchen staff]".

[The PC] was perceived by this informant to have already built up the network and that very little more was achieved by the project other than the inclusion of the ancillary workers and the connections which were forged between staff at the nursing homes and the hospitals.

This informant's point of view was in direct opposition to the assumptions on which the project was based, namely the need to treat the whole person through cooperative team-work. The importance of cross disciplinary cooperation was expressed succinctly by a specialist in pain management (S.T.) from the Flinders Medical Centre at a video conference. He stressed the need to empower carers to improve the overall quality of life of palliative care patients. This was supported by other participants. For instance a carer (M.W.) who had been invited to participate stressed that in her experience by demystifying pain management caring at home was made a little easier and it that it was better to feel in control of the technology and drugs than to feel controlled by them.

## THE CONTENT OF THE VIDEO CONFERENCES AND THE IMPACT OF ADULT LEARNING ON COMPETENCY AND CONFIDENCE

There were seven video conferences in all. Two covered the needs of carers with particular emphasis on the ancillary staff, one covered pain management and one covered the legal aspects pertaining to living wills, the rights of patients, the responsibilities of carers and euthanasia. The panel comprised qualified professionals such as a clinical psychologist, two medical specialists in the field of pain management, a social worker, a counsellor, a specialist nurse and two carers who had coped or were in the process of coping with home-based palliative nursing.

A review of some of the tapes of the video conferences showed how at each conference the participants gradually warmed to the topic under discussion. The initial conversation appeared strained as participants nervously

attempted to overcome their resistance to using a microphone and talking to a television screen. Technical aspects dominated the first few minutes, whilst the sound system and the focus of the camera were adjusted. One of the obvious sources of tension which was particularly evident when discussing aspects such as the dosage levels of drugs and the right to administer drugs, was the anxiety of saying something which would be regarded as unacceptable or possibly an indication of misconduct. It was extremely difficult given the small face-to-face community for people to discuss cases openly. Added to this was the knowledge that everything being said was being videoed and recorded in the presence of leading medical and legal experts and an ex politician. This topic would have been better handled by means of hypothetical case scenarios and a formal panel discussion.

The following points were highlighted as areas of new learning:

**The management structure in hospitals and nursing homes**

Domestics are part of the caring team and patients frequently prefer to talk to them because they are not professionals. As D.R. pointed out, people confide in those with whom they can personally identify. Auxiliaries can be perceived to be more accessible and more likely to understand the point of view of a patient. Added to this auxiliaries spend a great deal of time with them either cleaning rooms or serving meals. This time spent with patients often provides the opportunity for conversation. As R.H., a clinical psychologist from the Flinders Medical Centre stressed, time spent talking is as important in pain management as the drug therapy. The issues around the rights and responsibilities of patients, professional and ancillary staff were discussed in some depth. It became clear that the role played by the ancillaries is only beginning to be recognised and that there is no provision for counselling them at present in hospital and nursing home management structures.

**Pain management**

Pain management such as post operative pain, birth pain, terminal pain management, arthritic, osteo pain were discussed. It was emphasised that the meaning of pain made a difference to people, therefore it is essential not to regard pain as merely physical. In managing pain the whole person needs to be considered. Participants were advised to do obvious things first, such as finding out what the patient means by pain versus discomfort. They also discussed the value of patients deciding where they wish to be treated. Epidural for pain relief at home can be better for some people than being in an hospital environment.

A central point made was that palliative care is about understanding the needs of the patient and the meanings which they attribute to their situation. Without this empathy, caring becomes mechanistic.

The following issues were also addressed:

- defining different levels and types of pain: visceral, bone, differentiation pain (nerve pain). They were referred to Professor Ian Maddocks' book
- the role of natural therapy is acknowledged by the Pain Clinic at Flinders Medical Centre

- making the patient comfortable by using appropriate mattresses, prescribing analgesics which can deal with inflammation-related pain together with drug therapy.
- rebuilding the patients quality of life wherever possible
- the value of alternative therapies such as aroma therapy and hypnosis in some cases
- the different approaches to managing acute and chronic pain
- problems in dealing with bone pain which can at times only be dealt with when the patient remains still. The dosage of drugs under these circumstances was discussed, such as moving from simple analgesics to weak opiates to strong doses of methadone. The pharmacological value of morphine and Heroin which is illegal in Australia was discussed. The opinion that Heroin's illegality is not a problem, because pharmacologically it is similar to that of morphine, was addressed
- non professional carers discussed the value of home care and their being empowered to know what each drug is for and how to use the technology.

**Grief counselling**

- what to say to relatives of dying patients
- what to say in order to comfort patients, thinking of the relatives point of view.

**Making dying patients comfortable**

Dietary needs were addressed by a visiting dietitian, but it was difficult to get this across to some of the staff. Problems were identified in the management of organisations, such as resistance to change, for instance when the cook wanted to prepare different meals there was little enthusiasm for the idea because of staffs entrenched attitudes to the process of dying.

Another related issue associated with resistance to change was that staff are afraid that change would mean extra work for them without any extra remuneration. Staff already have to do too much to do. As a result there was perceived to be some apathy amongst staff. The group leaders expressed this opinion as follows:

> "The staff said: 'I have done my job, now I am off', they do however work very hard , there are no slack periods..."

**The difficulty of changing attitudes towards dying patients**

Participants in the video conferences said that staff did not see the worth of improving the quality of dying. The attitude was "why bother to change menus it won't cure them".

**Whether patients have the right to choose treatment or refuse it**

The realisation that some elderly patients take the decision that they choose to die and do not want to eat. Their role in this situation was discussed in terms of the new legislation discussed by experts in the field of legislation on Living Wills.

One of the video conferences dealt with the legal aspects associated with Living Wills and topic of euthanasia and the general rights of patients and the responsibilities of carers.

**The care of aggressive patients**

Case studies of aggressive patients were shared and appropriate holistic approaches discussed.

**The needs of ancillary staff**

- domestics talked about death and dying and how it affected them
- communication with domestics and other ancillary staff was raised as a crucial area for development in hospital and nursing home management policies.

To sum up, a greater understanding of a holistic approach to care which needs to be rooted in new communication styles in hospital settings.

**The extent to which there would be continued support for one another when the project ends**

The sustainability of the project is possible in the areas where the PC is active and could play a vital role in facilitating a more holistic approach to palliative care. This was summed up by a participant who stressed the importance of making meals appropriate to the needs of patients, but also presenting them with care: a flower on a tray can be an important means of comforting a patient at meal-times and can be as relevant as high powered pain management, because it can contribute to raising the morale of the patient.

**Extending the support network to other parts of South Australia**

An outcome of this pilot exercise could be the application of the combination of interactive video discussions and support networks to other areas requiring community development.

**DIAGRAM 4: FORGING LINKS FOR COMMUNITY DEVELOPMENT THROUGH ACTION RESEARCH**

ADELAIDE METROPOLITAN AREA
Expertise was drawn from professionals with local and international experience
COMMUNITY CONTEXT OF THE BAROSSA
Coping strategies of ancillary workers, volunteers and home carers
ORGANISATIONAL CONTEXT
Ancillary, professional and volunteer worker coping strategies within the organisation
WITHIN THE HOME
Individual coping strategies

The project aimed to link the individual palliative carers, both professional and ancillary workers, in home and institutional environments in the Barossa with the expertise of professionals in Metropolitan Adelaide.

Overall those who participated gained in their awareness of the holistic nature of palliative care.

## CONCLUSION: THE MOST SUCCESSFUL OUTCOME OF THE PROJECT AS FAR AS THE GROUP LEADERS AND THE EVALUATOR WERE CONCERNED

The most successful outcome of the action research was the way in which the hierarchical nature of the professional structures in hospitals and between hospitals and nursing homes was addressed.

An analysis of the data revealed that the hospitals and nursing homes tended prior to the project to operate in isolation from each other. This was perceived to be because the hospital staff considered themselves to be superior to the nursing home staff.

Within each organisational context the staff also operated in isolation from one another, because of professional divisions within the nursing staff hierarchy between registered and unregistered nurses and between the professional staff and the ancillary workers.

**Impact on organisational culture**

The network had considerable impact in the case of one nursing home in so far as nurse-ancillary worker relations were concerned. It improved team work and opened channels of communication.

Despite some of the negative feedback outlined above there was universal agreement that ancillary staff had benefitted and that in this way the relations in the hospital between the staff improved. The hierarchy between nurses and non-professional staff had been very marked in both hospitals and nursing homes in small country towns of the Barossa Valley. As a result of the project there is communication across the professional and non professional roles.

In terms of motivation and morale in a hospital setting this has been important in Kapunda and Tanunda. It had no impact at Angaston where the hierarchy is marked.

The ancillary workers responded with enthusiasm where they were given the opportunity:

> "The girls felt so thrilled to be included in the nursing scene. We used not to talk to the kitchen staff. It broadened the scope of the caring team. They do not have support to deal with the feelings they face when someone has died. It must be even worse in nursing homes where people who one has grown close to over time dies."

The group leader was enthusiastic about the visit of the dietitian who "made a good impact".

The group leader based at the interdenominational church organisation did not succeed in setting up a workable network. The networks on the whole were based at hospitals and at two nursing homes. Unfortunately the attempt to draw in a wider number of community-based volunteers through the Ecumenical centre was unsuccessful. The reasons for successful and unsuccessful networking were discussed above.

The most important spin-off of the project which emerged as a result of unstructured interviews was the development of an understanding of the need to forge intimate communication networks across the professional roles and disciplines within the palliative care team.

There is still a great deal of work to be done in order to improve the communication within and across professional roles. For instance one of the group leaders said that she could achieve little because as a registered nurse she did not have enough status in the hierarchy to be a leader, because no one was prepared to follow her!

It became apparent through informal discussion that the director of nursing did not support the project at the hospital where this informant worked, because it was considered unimportant. This director of nursing was reported to believe that the PC could manage on her own with the support of the nurses and general practitioners. At this hospital there was little understanding of the need for a palliative care network to support a team ranging from domestic workers, cooks, hairdressers, nurses and doctors who needed one another in order to provide holistic care and to counsel support one another and allow for debriefing in order to manage stress and prevent burnout.

## FOOTNOTES

- Ethnography is based on a process of gathering data on the lives of people through participant observation, case studies, networking and recording field notes. Ethnographic research developed within the discipline of Social Anthropology.

- Triangulation is a term derived from navigation. It involves using data from one source to check out the reliability and validity of data from another source, in so doing we can ascertain whether data from one source contradicts, supports or extends the data from other sources.

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## CONCLUSION: LESSONS LEARNED USEFUL FOR SIMILAR PROJECTS ELSEWHERE

The conclusions of this report are essentially inconclusive and can only modestly suggest what needs to be taken into account if a similiar project were to be launched at another time and place. And the lessons of this project are, of course, particular to the personalities, place, timing and the overall thinking and strategies of the project team, which may not not arise in the same combination again. Yet it is equally clear that there is some seasoned advice to be noted, on the basis of personal reflections about what was learned from the experiences of the project. What follows, then, are the thoughts of the project director, taking account of the first hand account of the Barossa based project worker, in telling the story of the unfolding of the support network at different stages, and the observations arising from the independent evaluation conducted by Dr McIntyre and her student assistants.

The spirit of my remarks are on the basis of what I ***would do and take into account*** if a similiar project were to be undertaken. These ideas are presented in a sequence of sub-headings.

### THINKING ABOUT THE CONCEPTION AND OVERALL DESIGN OF ANOTHER P.C.S.N. PROJECT

The core values of the project are essentially about helping palliative care workers from all the professional, service and ancillary occupations, as well as volunteers, home carers and other involved people, to work collaboratively together as a team (***the holistic model***) for the purposes of mutually supporting, sharing information and learning experiences and generally empowering each other, so as to improve the quality of palliative care services to patients, families and friends, both in a hospice or hospital, and home and community setting. The project has to be about achieving non-hierarchical, inter-discipline, reasonably open and democratic inter-personal communication between the inclusive range of PCWs, in which the usual boundaries of role and status are implicitly acknowledged but do not act as barriers to honest communication and collaboration, for the sake of continuous quality service improvement. This means that the usual dominance of bio-medical thinking gives way to a holistic and person centred approach, much of which is well underway both in spirit and form in the more innovative reaches of palliative care.

For such an idea to actually work on an everyday basis members of a palliative care support network (PCSN) have to be serious about wanting a voluntarily chosen group arrangement for pooling and sharing the full range of working experiences. This is much more than mere information exchange for it has to be about being interested in the ordinary democratic dynamics of small group relations and being free to express oneself openly and respond to the needs of others in a sympathetic, active listening way. In some respects group membership demands that often very busy and hurried PCWs slow down enough to give themselves and others time for gentle reflection. Sensible time management also goes along with a commitment to open learning and mutual support in a group environment, if any scheme is to succeed. Further to this, there needs to be enthusiasm from senior and middle management, especially in hospital and nursing home settings, to

lend tacit encouragement for PCWs to legitimately meet their support and learning needs through a flexible group membership.

Another important feature of the group is the recognition that in all the learning and reflection that should arise there is ***no such thing as a one best or right way*** in doing palliative care work, so as to avoid things becoming dogmatic and overly concerned with method and function, at the expense of letting people learn in their own way from variously perceived and felt experiences, as the basis of sharing them with others.

It is easy enough to outline these ideas and make them sound like prescriptions, whereas the reality is that many of the underlying principles of a PCSN really highlight some of the problems of occupational and organisational rigidities that abound in the health care system and serve as a deep bedrock which makes the process of change through ideas about the social relations of communication and collaboration slow and difficult to effect. Some of these problems are compounded in the relatively isolated and conservative workplace traditions of rural and remote health care service locations.

One of the acid tests of a successful PCSN is the ability to incorporate volunteer PCWs and ancilliary staff as welcomed and valued members, not an easy task, especially for the latter group who are inclined to be regarded as marginal players and down play their own special contribution. The ethos of the PCSN idea would not be fully realised if it were to become dominated by medical and nursing interests for many other value adding aspects of palliative care are taken on by volunteer and ancilliary workers and an even wider circle of other small part players in the overall provision of a quality service which reaches into the home of the terminally ill and the wider community. A very practical test of the workability of a PCSN is the capacity to provide regular debriefing to PCWs, particularly those operating in a non-professional, support role as a volunteer and ancillary worker. There need to know and understand what is happening in palliative care and the ability to respond to their needs through a group support process is an excellent measure of success and a tangible goal for everyone to concentrate upon.

## DOING A NEEDS ASSESSMENT FOR STARTING A P.C.S.N.

The obvious starting point is that an expressed need for and a genuine commitment to the formation of a quality service focused PCSN has to be shared by a sufficiently enthusiastic number of PCWs at a local level of operations. This usually requires leadership from a palliative care nurse or a local general practitioner with a special interest in palliative care and ideally involves the support and co-operation of Directors of Nursing and other key gatekeepers to ensure there is a positive organisational climate for a PCSN to take root.

It is also essential to form a close partnership with tertiary education providers who have video conference facilities and are willing to provide access to them, usually on a fee for service basis or some other arrangement. Indeed the thinking about a PCSN has to be very much about how to form and develop easy collaborative relationships with any other relevant community agencies that can lend support. In smaller and often self reliant communities, such as that demonstrated in the Barossa valley, it is

sometimes easier to identify people and institutions who might become active supporters.

It is also important to make good contact with key people and institutions in the cities and centres of population where a critical mass of relevant knowledge and experience can be more easily found, not just of palliative care but also those other related aspects such as adult education and open learning. It needs to be said that without good connections with such human and technology resources PCSN in the more rural and remote locations will be difficult to sustain. That was certainly a key factor in the Barossa valley, which was additionally fuelled by a wide circle of enthusiastic people willing to experiment with some new ideas.

## GROUP LEADERSHIP AND ACTIVITY

Following from the last sub-section, a PCSN works best from the basis of having a locally placed and experienced PCW with the vision, local standing and leadership qualities to foster an initiative from conception through to everyday practice. Although the evaluation clearly showed what kinds of networks perform better than others, it is still preferable to encourage network group leaders to develop their own ways and means of making things work and then reflect upon what counts as success in the eyes of the members.

Equally important is to find a volunteer willing to undertake some of the back up and support tasks, for whoever takes on the role of co-ordinating a PCSN will find that in no time there is a need for some administration to sustain the momentum and keep interest focused.

Thereafter each support group that is formed needs to be led by a PCW with some knowledge and experience, the confidence to communicate easily with people in different roles and status positions, and, more importantly, with the enthusiasm and commitment to work with a regionally placed palliative care co-ordinator, akin to the current arrangement throughout South Australia, and provide the energy and leadership for the network members. All community development type activities depend upon the supply of such enthusiastic human resources with the personality and inter-personal communication skills to get things moving.

It follows that members of a PCSN must also be serious and committed to making things happen, for anything less weakens the sense of need and purpose leading to its demise.

## LEARNING AND COMMUNICATIONS

There are two main ways of learning in a PCSN. The first is through informal exchanges focused on the learning benefits of practical experiences and views arising from doing palliative care work. Such exchanges are an integral part of providing mutual support in a reasonably organised way. In addition to meeting and exchanging ideas and experiences on a face-to-face basis next best is the use of the telephone for focused discussions. It was a pity that the Barossa project never properly explored the potential for telephone conferences, which are becoming commonplace in distance learning schemes.

The second means is through open learning, which because of the distance involved needs to be mediated through televised and interactive video conferences and telephone conferences, the former being particularly attractive as it enables a record to be kept of proceedings with video cassettes for later playback. It is a short step to the formation of study groups, maybe as a feature of a quality circle dealing with all aspects of palliative care service provision.

The Barossa valley experience underlined the need for an introduction to using video conferences to most effect, notably some simple introduction to the use of the technology and adequate preparation for the actual 'on-air' proceedings so that the exchanges are well focused and informed with the provision for debriefing discussions afterwards. What is also important is to ensure that the content of video conferences are based on the perceived learning needs and interests of network members, a process which requires group leaders and co-ordinators to communicate frequently with other PCWs. This is what is meant by developing a 'bottom up' strategy for mutual support and focused learning in the PCSN.

## FINAL THOUGHTS

From my standpoint the project demonstrated the relevance and value of an adult community approach to the development of a support and learning network, which happened to be about palliative care but had obvious potential for comparable needs in the broad field of health and social welfare provision. The project may even have made some small change to community consciousness about palliative care and lowered the taboos about death and dying.

There were some shortcomings experienced in the project, which was more to do with the problems of getting some local people to grasp the significance of the ideas in a short time and make best use of the opportunities, arising as they did from the expressed needs of country based PCWs. But overall the project was worth doing for it did meet with a mostly positive response from the PCWs it was intended to serve and demonstrated in tangible form many of the original visions of the PCSN idea.

Perhaps the most significant point of the project was the high level of co-operation between institutions and agencies in health and education, mainly of a personal kind as the people active in these fields of human services come across each other quite naturally in the course of their roles and responsibilities and tend to share common enthusiasms for doing innovative things. Indirectly this network of collaborating professionals and volunteers underlined the naturally holistic nature of community based palliative care. In my view this highlights and contrasts the rather arid nature of the current policy of reducing the spirit and form of palliative care to the rules of cost accountancy and economic rationalism, under the term *casemix*, which is strong on calculating the price of everything except the un-costable value of human giving, compassion and love, which are the foundation stones of the most human of human services.

Thus the answer to my own rhetorical question is that I would do a similiar project again but with a more experienced awareness of some avoidable pitfalls.

# THE ORIGINAL OUTLINE PROPOSAL

**Support Services for Country Based Palliative Care Workers**

The conference for Country Palliative Care Services identified, amongst other matters, a need for a support scheme for both professional and volunteer workers, particularly but not exclusively focused on rural and remote areas, referred to as country services.

Clearly, the issue of continued funding, to maintain and further develop the already rapidly expanded network of palliative care services in SA, is a cause of uncertainty. Moreover, the nature of provision by structure and process is still evolving. But within those constraints and forces lie the immediate concerns of achieving a quality service through successful team working and all that is implied in the need for information exchange and other forms of communication.

Through discussion in a forum dealing with country care services it was generally agreed that a support scheme would have to comprise an educational focus (knowledge and skills, attitudes and values) and a psycho-social dimension, which was intended to be affirmative and empowering (not based on a deficit model), and concerned to identify and resolve issues of practice through what is called action planning.

Given the considerable knowledge and experience gained through practice there is a need to formalise this learning by developing a performance review process (not an appraisal scheme which tends towards a deficit approach to work role behaviour). Specifically, such a performance review process would need to combine self with peer review in a non-threatening, developmental way and which was derived from an analysis of typical concerns of work role practice (based on experiences with patients and families, other professional and volunteer workers, organisation and management of various institutions, etc). The content of what is really a concerns based SWOT analysis - personal strength and weaknesses, opportunities for change through problem solving and action planning, and threats whether real or imagined - would form the basis of self and peer review and thereby the means of sharing information and ideas within a widening circle (as in teams and quality circles).

Out of this the precise forms of support needed by palliative care workers would come from the basis of experience and lead naturally into a caring and sharing network (via mentoring, teleconference and other forums) underpinned by an educational programme founded on a 'need to know' and self selected way serviced by the various resource centres.

To achieve these objectives it is necessary to embark upon a consultative process in which palliative care workers (professional and volunteer team members) are given the opportunity to develop a performance review scheme based on 'real life' problems of work role and deeper felt experiences of such challenging personal work. At a guess these problems are likely to focus on the following -

1. Palliative care work with patients covering the medical and psycho-social aspects of dying and death.

2. Death, grief and bereavement work with the relatives and close friends of patients.

3. Inter-professional relations focused on the problems of working collaboratively and effectively to quality standards.

4. Dealing with the bureaucratic politics of palliative care provision, notably access to services and resources in order to work optimally on behalf of clients.

5. Other aspects of palliative care work not covered by the categories above.

These matters refer to the **content** areas of a performance review. What happens next is the setting up of an agreed **process**, using group leaders for close up work and feedback of an affirmative and constructive kind, reinforced by regular teleconferencing focused on issues of a broader policy to practice kind which is shared on an experiential basis by a wide circle of palliative care workers dovetailed to an educational programme on current trends in all aspects of the work.

It is essential that the performance review model is developed from the 'bottom up' basis of practice and is genuinely owned by workers as their ways and means of empowering themselves. It seems useful to work towards a performance review model that incorporated four 'givens' as indicators of effectiveness, viz -

- an agreed idea of what quality work means in palliative care
- an agreed set of ideas regarding work satisfaction embracing the emotional, intellectual, spiritual and other well being challenges of the role
- an agreed set of ideas regarding the skill requirements as well as deeper level critical awareness and value clarification aspects of the work role
- an awareness of the 'bottom lines' of cost effectiveness and resource limitation as an externally imposed discipline within which work has to operate.

**Memo: Education and Research Committee:**
**SA Hospice and Palliative Care Association**

Since our meeting I contacted the Director of the Flinders Medical Centre Volunteer Service to explore further possible avenues of support for an action research project dealing with the establishment of a support network for palliative care workers in country areas. My choice was a good one for both Helen Watts and Helen Doudle expressed support for the idea and commitment to a course of action to develop thinking and a plan. These were the main points arising from our meeting, viz-

- **Point one:** The idea of a support network comprises three related elements, namely:

1. The setting up of a group leader or "buddy" system in which those with more experience of palliative care work help those with less knowledge and experience to talk about the everyday concerns and to pool thinking about practice. Ideally the group leaders would be close at hand and would commit a regular period of time to listen and share with a very small group of workers the experiences of palliative care. From this process staff development needs would be expressed that would constitute the material for the next element of the cycle of support.

2. The use of a teleconference link widening the circles of consultation across a geographical area in which a facilitator would enable people to talk about their experiences and needs in a more focused and problem solving way. Members of the teleconference networks would be encouraged to continue talking to each other informally at other times and to report back to the group leaders on the content of the discussions as part of their regular meetings.

3. As it is very likely that needs will arise for more formal staff development regular "classrooms of the air" will be utilised through the TAFE system to provide a distance learning forum. The content of these training and development forums can be further discussed via the teleconference network and meetings with group leaders.

In all of the ways described above it should be clear that the network of support has both informal and formal content with the weight of the bonding process located at the "grass roots" with the group leader or buddy system.

- **Point two:** It is most important that the support scheme is designed equally for paid and volunteer palliative care workers on the assumption that they are partners in a team working context sharing the same problem of geographic isolation from others and the "centre of things" as it were.

- **Point three:** It is advisable to develop the support network on a trial basis with an in-built evaluation confined to a clearly demarcated geographic area outside the metropolitan district. The establishment of a proven scheme would be easier for a substantial funding body to support across the state as a whole.

- **Point four:** As a rough calculation about $10,000 to $15,000 would be required to pay for a part time project co-ordinator, consultancy support and guidance, and other running costs. The project would need a year to get started and evaluated.

- **Point five:** It was agreed that a small group of relevant people should be invited to discuss the project using these notes as a guide. I have secured the interest of two colleagues from the university, one expert in the formation of small communication groups and the other in distance learning, along with my interest in action research and project evaluation. It is also possible to attract the interest of communication consultants from Telecom would know about teleconferencing. Helen Doudle of the FMCVS has undertaken to look for possible sources of funding.

## SHORT REPORTS ON THE PROGRESS OF THE PROJECT

**Action Research Report: The Development of a Support Network for Palliative Care Workers in a SA Country Area**

Published in *Hospress* (The Newsletter of the South Australian Association for Hospice and Palliative Care) October 1992

At one of the group discussions during the 1991 Conference *"Working Together"* a common concern was expressed, by both professional and volunteer palliative care workers in country areas, for some kind of personal support and training scheme focused on their needs. Participants in the forum acknowledged that palliative care workers in ***any*** location shared the same need for information and ideas exchanges, to sustain morale and the values and practices of team working, as well as regular access to knowledge developments in the field so as to continue to provide quality services. It was also agreed, however, that workers in country areas of South Australia, at greater distance from the critical mass of knowledge and practical support characteristic of human services in the metropolitan conurbations, did experience a relative sense of isolation and a keen feeling of the need to be in touch, both with each other and to "best practices" elsewhere.

There is nothing new about the problem. A very good recent study of the staff development needs of nurses in rural and remote areas of SA, by Patricia Buckley of Flinders University, points to the same sense of relative deprivation arising from the tyranny of distance and isolated working.(1) Similarly, staff attached to the Flying Doctor Service are addressing their needs for inter-personal support, training and development.(2) It is only proper that palliative care workers in country areas attend to their perceived support and training needs, in a field of human caring in which there is much to be learned from experience and research.

Arising from the conference I made an outline action research proposal which has been discussed by several more qualified people working in palliative care. In response the Hospice Foundation has very generously under-written the pilot stage of an attempt to develop a support network for palliative care workers, making no distinction between paid and volunteer staff, based in the Barossa Valley. What follows is a brief outline of the main ideas of the pilot project.

The key point to note is that the project is best described as an action learning one, which means that the main directions and ideal outcomes are clear enough to make a start but the process involved in reaching a satisfactory stage of mature development has to be learned by the experience of trial and error. If the pilot project can be described as successful, say in a year from now, it is intended to make a full scale proposal for funding the development of a state wide scheme.

There are two developmental stages to the project. The first is to establish a network of self supporting small groups of palliative care workers, who will either meet or talk to each other by telephone regularly about their concerns arising from the practice of their working experiences. It seems practical to

form groups based in and around the local hospitals in the Barossa Valley, which obviously serve as important focal points, although some other location might equally serve the same purpose. Each group will probably need an appointed coordinator who will try to keep the network of members, ideally of around 8 to 10 people, talking to each other regularly and focused on their personal and professional development needs arising from work experiences in palliative care. It is anticipated that this concerns based approach to needs will produce two broad agendas. The first will probably focus on personal needs for a sharing and talking forum in which workers can explore their experiences with others close at hand. This might be described as a very developmental form of performance management, without any hint of appraisal and summative judgements. The second agenda reaches outward to the more formalised body of knowledge that is being accumulated on the basis of research and documented experience throughout the world of palliative care. In that context the Adelaide metropolitan region provides, close at hand, a considerable resource of knowledge and learning for staff development purposes.

The main player in the formation of the various support networks, and what follows from their concerns and identified needs, is the project worker. Through the valuable contact work of Felicity Hage, the only specialist palliative care nurse working in the Barossa Valley, a part time worker has been appointed to set up as many self supporting groups as seems viable to get the project to the first stage of development. Diana Spencer, who lives in Lyndoch, currently a TAFE lecturer involved in community services courses with a nursing background as well as other relevant experience, is ideally suited to the task. Like other community development projects this one requires a person with the skills and the tenacity to work closely with others, tapping into the enthusiasm as much as the expressed need for "something to be done" so that thoughts turns to commitment and actions. Clearly a light touch is needed to ensure that the support groups actually function but without getting in the way they unfold and internally operate. Much of the contact work will have to be done with the support network co-ordinators and the mentoring they may require will have to emerge through experience.

With the support groups working, which means they meet/talk to each other regularly about their working experiences and needs, the "shopping list" of agenda items for training and further development is communicated to the project network co-ordinator. This becomes the basis of a planned programme of staff training seminars using the existing audio-visual learning networks established by state government and particularly the South Australian TAFE system, providing "on air" access to knowledge and expertise on palliative care matters located in the Adelaide metropolitan area and beyond.

For this scheme to work it is necessary to conceive of it as a learning contract; most importantly between members of the various local support groups and hence through the network co-ordinator to the distance learning facilities that bring a wider body of workers together for the purpose of following a dialogue with acknowledged leaders in the field of palliative care who can report on research findings, policy matters, ethical concerns and whatever else comprises the "need to know" of the country based practitioners.

Diana Spencer is the trail blazer who has the challenging task of establishing the support networks, starting from the local bases and moving to the whole

of the Barossa Valley and engaging the metropolitan resources in due course. She will be supported by an advisory/steering group comprising people with relevant knowledge and expertise, including Felicity Hage who will doubtless work closely with Diana. To my knowledge the literature based sources about schemes of a comparable kind elsewhere are limited so much of the learning will have to be experienced directly, which seems fitting. (971)

Notes:

1. P Buckley "What can be done to assist Registered Nurses in rural and remote parts of South Australia?" Current and recent past research 1991.
2. Information supplied by J Barclay of the School of Nursing, University of South Australia.

**Second Action Research Report:**
**Developing A Palliative Care Support Network.**

Published in *Hospress* July 1993

In a previous edition of the Newsletter I outlined the origins and leading ideas of the planned development of a palliative care support network, located in the Barossa Valley. During the passage of time there have been enough satisfactory developments to provide a short progress report which is the purpose of this paper.

In essence, the idea driving the project was to find an organised response to the frequently noted appeal of rural and remote country based palliative care workers for *"someone to talk to and someone to listen"*. Thanks to the generosity and spirit of inquiry of the Southern Hospice Foundation the project properly started work at the beginning of 1993.

With the appointment of Diana Spencer, as the project worker living in the Barossa, rapid progress was made in forming eight small groups of palliative care workers based around the three local community hospitals and various aged care facilities. Diana's inside local knowledge and contacts made this vital aspect of the project much easier to achieve than would have been the case if someone outside the valley had been engaged. The Palliative Care Co-ordinator for the Barossa also played a key part in the group formation process, with interest and goodwill doing the rest. The groups were always intended to comprise all members of the palliative care team, that is, not only doctors and nurses but also other allied health workers, ancillaries and volunteers.

Each group has an appointed leader whose task is to keep the members talking to each other about their "needs to know" about any aspects of palliative care which concerns them. The assumption is that regular talking and sharing of ideas and experie ices goes a long way to mitigate the sense of unsupported working in the re tive isolation of a country area. Meeting on an everyday casual basis through the shared experiences of work is supplemented by telephones conferences or other more focused assemblies. In due course the need for more systematic general knowledge and particular information leads to the second stage of the project development, namely, the interactive video conferences with specialist palliative care workers based in the metropolitan area of Adelaide.

At the time of writing (June 1993) three such conferences have been held. The first two focused mainly on various aspects of pain management and drug treatments, along with some attention to the psycho-social problems of care, both in a hospital or hospice and home setting, using case histories as the basis of a question and answer approach. The group leaders were the main participants in the two conferences whereas the third one, by deliberately attending to the theme of the basics of palliative care drew into the circle the non-medical and nursing worker, that is, ancillaries and volunteers, whose needs to know are more about the human relations aspects of caring and communicating to patients and their families and friends. In all three sessions it is clear that there is considerable interest in improving the quality of palliative care through confident and competent practice.

The project has been very fortunate in attracting the active support and involvement of some TAFE staff at the college in Nuriootpa whose expertise and access to the video conference facilities has been excellent. One of the likely outcomes of such an easy collaboration is a planned video conference with general practitioners working in the Barossa and nearby Gawler. It is hoped to obtain the support and participation of Kabi Pharmacia who market the pain management drug MS Contin.

Throughout the progress of the project reports have been given to the Hospice Foundation and Palliative Care Co-ordinators in South Australia have been supplied with an advance copy of my paper to a conference in Toowoomba on health care in rural and remote parts of Australia.

Finally, another colleague from the university, a social anthropologist teaching on a community development program, has agreed to undertake the supervision of two students to conduct a formative evaluation during September focusing on the group formation and learning aspects of the project.

It is very easy to let early progress obscure some of the awkward questions and possible shortcomings of the project. The chief of these is whether the support groups will sustain their own interest and momentum once the project has been wound up. Other questions deal with the membership of the groups. The project would be missing the point if they only drew on nurses, for the team based focus of palliative care should include doctors, social workers, allied health staff, ancillary workers, volunteers and others, to be really representative of the spirit and form of the work. And it is necessary to find out whether group members claim to have learned some new things since becoming involved. That is why an independent evaluation is necessary, especially if an approach is going to be made to the SA Health Commission for funding of a possible state wide scheme. They would certainly want to know if such support schemes really work, let alone how much it would cost.

**Report to the Executive Officer of the Hospice Foundation**

Palliative Care Support Network-Video Conference 7/4/93:

The second video conference (VC) was a mixed success. The contributions from the expert panel were excellent, both for the quality content and dexterity of their answers. I was disappointed, though, by the modest

attendance of the group leaders in the Barossa and for the rather passive way in which they interacted with us in Adelaide. The second point can be addressed by getting the project worker to play a more active facilitative role. But the first matter raises the deep questions about the character of the group leader supported networks, for it must soon stand alone when the project money and the activities of the worker fade from the scene.

The two problems of the group leader led support groups have always been about their representative nature and the energy they put into identifying needs and expressing them through such forums as the VCs. I'm still not sure we have really tapped into the wider network of people involved in palliative care in the Barossa, beyond the nurses and a one doctor. Clearly the matter needs more attention and active marketing of the value of a support network amongst a wider constituency of involved players, most notably volunteers, medics and social workers in the community as well as health care institutions. The next VC which is solely about the basics of palliative care will be a real test of the group leaders and project worker, for we must get more people along, of a wider circle, and more actively engaged with the interactive nature of the VC. I shall urge the project worker to focus her energies and do some preparatory ground work so that we can make the best use of the VC.

It seems a good idea to explore the possibility of adding value to the project by targeting one of the key player groups in palliative care, that is, the physicians involved in the several general medical practices in the Barossa Valley, and running a VC just for them focused on the concerns they have in their work. This seems a good opportunity to market the palliative care book written by Ian Maddocks and use it as a taster for the VC and a question/answer forum with the doctors at Daw House (or elsewhere). I would need to discuss this with Ian and Roger to plan the best approach and possibly some modest additional funding.

## APPENDIX 3

# OCCASIONAL LETTER TO OTHER PALLIATIVE CARE CO-ORDINATORS IN COUNTRY AREAS OF SA

Dear Palliative Care Co-ordinator

You may recall that I wrote last year about the development of a palliative care support network in the Barossa Valley, funded by the Southern Area Hospice Foundation, enclosing a brief description of the project. Felicity Hage, because she works in the Barossa, is familiar with the project and has been an active participant at the two video conferences held so far through the TAFE distance learning network. I have since talked briefly with Trish Millar at Mount Gambier at the recent *Too Burnt Out to Care?* conference.

With no expectations or requests whatever, I thought you might like a copy of a paper I shall be giving at the national conference on health care in rural and remote Australia, to be held in Toowoomba in mid August. I think it summarises quite well the evolution of the support network idea. Maybe you will find it useful in some way or other. Anyway you are welcome to a copy, providing it is not used in any official publication as it is copy righted to the proceedings of the Queensland conference and no longer mine.

Naturally, if you wish to make any response to the paper I would welcome your views.

## APPENDIX 4

# EVALUATION OF THE PALLIATIVE CARE SUPPORT NETWORK

**Support Group Membership**

The focus is upon the openness of the groups with questions based around who has joined and who might have been left out.

**Support Group Function**

The focus is upon the activity level of the group, such as how much they communicate and how they support each other, and the role of the group leader/mentor in holdings things together and giving direction and purpose.

**Learning Aspects Of The Support Group**

The focus is upon what new learning has taken place through the group support process both informally by "being together" and formally through the interactive video conferences, and how much group members have become comfortable with the learning technology used for distance communication.

**The Roles Of The Project Worker And Director**

The focus is upon the questions of how much they should try to influence and possibly direct the attention of the support groups, and the kinds of skills they need to provide effective back up support.

## APPENDIX 5

## PARTICIPANTS IN THE VIDEO CONFERENCES FROM ADELAIDE

**Southern Community Hospice Programme:**

| | |
|---|---|
| Janet Donnell | Lecturer in Palliative Care: Flinders University |
| Bette Dunsmore | Clinical Nurse Consultant (CNC): Flinders Medical Centre (FMC) |
| Karen Glaetzer | CNC: Repatriation General Hospital (RGH) |
| Virginia Hamblin | CNC: Daw House Hospice, RGH |
| Roger Hunt | Medical Coordinator: FMC |
| Ian Maddocks | Director and Professor of Palliative Care: Flinders University |
| David Roach | Social Worker: Southern Domiciliary Care and Rehabilitation Service |

**Western Palliative Care Service**

| | |
|---|---|
| Maria Brooks | Clinical Nurse |
| Mary Caminitti | Volunteer |
| John Pakos | Resident Medical Officer |
| Tricia Standfield | Social Worker |
| David Thorne | Medical Doctor and Director of the Program |
| Marg Venning | CNC |

**Other participants**

| | |
|---|---|
| Jennifer Cashmore | Chair: South Australian Association for Hospice and Palliative Care |
| Janine Haines | Chair: Southern Hospice Foundation |
| Russell Hawkins | Psychologist: Pain Management Unit, FMC |
| Chris McRay | Bereavement Counsellor: Blackwell Funerals |
| Simon Tordoff | Medical Doctor: Pain Management Unit, FMC |
| Marie Wood | Home carer |

**Video conference camera, operations and tape editing**

| | |
|---|---|
| Sylvia Healy | Light and Riverland Institute of Vocational Education |
| Geoff Williams | Adelaide Institute of Vocational Education |
| Polly Forrest | Daw House Hospice Volunteer |

**Observers**

| | |
|---|---|
| Lyndel Bone | Student: University of South Australia |
| Heidi Kliche | Project Officer: Southern Community Hospice Programme |
| Janet McIntyre | Lecturer: University of South Australia |
| Rosemary Rodigues | Chief Executive Officer: Southern Hospice Foundation |
| Amelda Trainor | Student: University of South Australia |
| Helen Watts | Treasurer: Southern Hospice Foundation |